

# **BAY AREA QUALITY MANAGEMENT SYSTEM**

## **FAMILY GUARDIAN SURVEY RESULTS**

**Medicaid Waiver &  
Consumers Transitioned to the Community**

**Year One Data (2005)**

### **FINAL REPORT**

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## Executive Summary

### *Background*

The California Department of Developmental Services (DDS) was awarded a *Real Choice Systems Change* grant from the Centers for Medicare and Medicaid Services (CMS) in 2003 to strengthen its current quality assurance and improvement system. One of the primary objectives of the grant is to develop a process for measuring participant satisfaction and outcomes. To achieve this goal, the Department implemented a pilot project in the San Francisco Bay Area across three sites: Golden Gate Regional Center (GGRC), Regional Center of the East Bay (RCEB), and San Andreas Regional Center (SARC).

The three-year pilot project has two overarching goals: (1) to provide data for the *Bay Area Quality Management System* (QMS), which is involved with the transition of people from the Agnews Developmental Center to community-based settings, and (2) to pilot an assessment tool that may potentially be used across California's 21 regional centers.

This report is one of a series of analyses prepared by the Human Services Research Institute (HSRI) to summarize the results of the grant activities related to the first goal stated above. Each report addresses a different target group and presents results of data collected using survey tools developed for the National Core Indicators (NCI) program. There are several NCI mail surveys designed to gather feedback from families and guardians. The two mail surveys used in this study include the “**Adult Family Survey**,” which is administered to families who have an adult consumer living at home with them, and the “**Family Guardian Survey**,” which is administered to families or guardians of consumers who receive supports outside of the family home. **This report presents results from the Family Guardian Survey, which was administered to two groups: (1) a sample of families and guardians of consumers who receive Medicaid Waiver services and supports outside of the family home and (2) to all families and guardians of consumers who transitioned from the Agnews Developmental Center to the community.** The two groups are analyzed together in this report. Results of the Adult Family Survey are presented in a separate report.

### *Methods*

The pilot project steering committee selected the National Core Indicators (NCI) instruments to be used as the data collection tools for this activity. These surveys are used across the country by 27 state developmental disabilities service systems and by one regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing national benchmarks for comparison purposes. The surveys are specifically designed to measure performance and outcome indicators. The committee selected these tools for their benchmarking potential and for their correspondence with the quality measure domains of interest to the California DDS.

The NCI Family Guardian Survey (conducted by mail) was administered by a private contractor, XenologiX. The first year of data collection took place in 2005.

## ***Sample***

At the time of the survey, there were 64 consumers who had transitioned from Agnews, and 7,901 consumers over age 18 on the Medicaid Waiver. Family Guardian Surveys were mailed to a sample of 1,223 families across the three regional centers. A total of 192 useable Family Guardian Survey responses were obtained.

## ***Positive Findings and Trends***

- Families generally report having enough involvement in planning and that case management staff are effective, respectful, and able to be contacted.
- Over 80% of respondents report that case managers provide them with needed assistance, and that their family member receives needed services. These findings are similar to the NCI state average.
- 93% of family/guardian respondents feel that the consumer's residential setting is a healthy and safe environment, and 92% express the same about the day/employment setting. The Bay Area results are slightly higher than the NCI state average.
- Staff turnover appears to be somewhat less of a concern in the Bay Area than in other NCI states. In the other states, 22% report that frequent staff changes are usually a problem, while in the Bay Area only 13% checked this response.
- The majority of family respondents report that providers involve them in making important decisions for their family members.
- Similar to the NCI states, just over half of Bay Area families report that their family members have access to typical supports and activities in the community.
- Approximately 80% of families reporting are satisfied with services and supports received by their family member. 85% feel that services have made a positive difference in their lives, and 83% report that their family member is happy. These findings are similar to the NCI states.

## ***Possible Target Areas for Quality Improvement***

- A lower percentage of respondents (65%) reported usually having enough information to participate in planning as compared to the national average of 76%.
- Ability of staff to communicate with consumers stands out as a possible concern. Of Bay Area respondents with communication as a concern, 15% report that support workers who are competent to communicate with their family member are "seldom or never" available. In NCI states, this figure was 4%. It would be useful to probe further into this issue to find out if the problem is related to staff having the skills to communicate in the person's primary language or expertise with alternative communication methods.
- According to the responses, 20% of families report lack of access to special adaptive equipment at least some of the time. Compared to the NCI state average of 13%, this appears to be an area of concern.

- Choice and control over support workers is reportedly low but in line with the NCI state average.
- Community *participation* is rated somewhat lower than the NCI states, with 22% stating that their family members “seldom or never” participate in community activities compared with 16% in the other states.
- 42% of families report that they do not know the process for filing a complaint or grievance. This is an area that warrants attention.

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## I. INTRODUCTION

The California Department of Developmental Services (DDS) was awarded a *Real Choice Systems Change* grant from the Centers for Medicare and Medicaid Services (CMS) in 2003 to strengthen its current quality assurance and improvement system. One of the primary objectives of the grant is to develop a process for measuring participant satisfaction and outcomes. To achieve this goal, the Department implemented a pilot project in the San Francisco Bay Area across three sites: Golden Gate Regional Center (GGRC), Regional Center of the East Bay (RCEB), and San Andreas Regional Center (SARC).

### ***Overall Purpose of the Study***

The three-year pilot project has two overarching goals: (1) to provide data for the *Bay Area Quality Management System* (QMS), which is involved with the transition of people from the Agnews Developmental Center to community-based settings, and (2) to pilot an assessment tool that will eventually be used consistently across California's 21 regional centers.

The specific goals of the pilot project are to:

- ♦ Support value based outcomes
- ♦ Keep people safe and ensure their well-being
- ♦ Ensure consumer and family satisfaction
- ♦ Identify and close gaps in the community system
- ♦ Develop a system with potential for statewide use
- ♦ Meet the expectations of the Centers for Medicare and Medicaid Services

In 2004, the project Steering Committee selected the National Core Indicators (NCI) as the best assessment tool to gauge participant satisfaction and designated a private company, XenologiX, to carry out evaluation activities.

### ***Focus of this Report***

The results presented herein represent information gathered through a mail survey of a sample of families and guardians of consumers who receive Medicaid Waiver services and supports outside of the family home and to all families and guardians of consumers who transitioned from the Agnews Developmental Center to the community. It is not possible to distinguish between the two groups in this report, since the groups were not coded separately in Year One.

Data collected from the two primary data sources are presented in this report by outcome area so that the Bay Area QMS can evaluate how well the measures inform the stated Outcome Performance Indicators, many of which correspond to the National Core Indicators domains. The data included here are from the first year of data collection (2005). Both quantitative and qualitative data are presented in an effort to capture the nuances of the experiences of families and guardians. The data are organized by the following domains:

- ♦ Information And Planning
- ♦ Access And Delivery Of Services And Supports

- ♦ Choices And Control
- ♦ Community Connections
- ♦ Satisfaction With Services And Outcomes

## II. METHODS

This section describes the survey tools, research methodology, and administrative procedures used to collect the data and to ensure the validity of the information gathered.

The pilot project steering committee selected the National Core Indicators (NCI) instruments to be used as the data collection tools for this activity. These surveys are used across the country by 24 state developmental disabilities service systems and by one regional center in California. The tools have been tested for validity and reliability, and they also have the advantage of producing national benchmarks for comparison purposes. The surveys are specifically designed to measure performance and outcome indicators. The committee selected these tools for their benchmarking potential and for their correspondence with the quality measure domains of interest to the California DDS.

### ***Overview of National Core Indicators***

In 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI) launched the Core Indicators Project (CIP). The project's aim was to support state developmental disabilities authorities (SDDAs) in developing and utilizing performance/outcome indicators and related data collection strategies. These indicators, along with the results from data collection efforts, would enable them to measure their service delivery system's performance, and inform future decision-making around systems change. The indicators, measurement tools, and results offered by this project provide SDDAs with a fundamental resource to improve system performance, and ultimately better serve people with developmental disabilities and their families.

CIP began in 1997 when its Steering Committee selected a "candidate" set of 61 performance/outcome indicators (focusing on the adult service system), in order to test their utility/feasibility. Seven states field tested these indicators by administering the project's consumer and family surveys and compiling other data. The results were compiled, analyzed and reported to participating states.

In the ensuing years, the original indicators, data collection tools, and methods have been periodically revised and improved under the guidance of the project's steering committee. In 2001, the project expanded its scope to include services for children with developmental disabilities and their families. In 2002, The Core Indicators Project (CIP) officially changed its name to the National Core Indicators (NCI) to reflect its growing participation and ongoing status. By 2005, NCI had grown to include participation by 23 states and three local developmental disabilities authorities.

NASDDDS' active involvement and sponsorship of NCI efforts continues to facilitate states' efforts to pool their knowledge, expertise and resources in this endeavor.

The following table illustrates current participation in the National Core Indicators:

Table 1 State Participation in NCI	
Alabama	Massachusetts
Arizona	New Mexico
Arkansas	North Carolina
CA - Bay Area Regional Centers	Oklahoma
CA - Regional Center of Orange County	Pennsylvania
Connecticut	Rhode Island
Delaware	South Carolina
District of Columbia	South Dakota
Georgia	Texas
Hawaii	Vermont
Indiana	Washington
Kentucky	West Virginia
Maine	Wyoming

### ***Family Indicators***

Obtaining direct feedback from families is an important means for states to gauge satisfaction with services and supports as well as to pinpoint potential areas for quality improvement. The results garnered from family surveys enable a state to establish a baseline against which to gauge changes in performance over time. In addition, these results permit a state to compare its own performance against other states. The table below details the Family Sub-Domains, Concerns, and Indicators, and identifies the survey instruments in which the indicators are explored.



Table 2 Family Indicators			
DOMAIN	<b>FAMILY INDICATORS</b> The project's family indicators concern how well the public system assists children and adults with developmental disabilities, and their families, to exercise choice and control in their decision-making, participate in their communities, and maintain family relationships. Additional indicators probe how satisfied families are with services and supports they receive, and how supports have affected their lives.		
SUB-DOMAIN	CONCERN	INDICATOR	DATA SOURCE
Information & Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.	The proportion of families who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand.	All Surveys
		The proportion of families who report they have the information needed to skillfully plan for their services and supports.	All Surveys
		The proportion of families reporting that their support plan includes or reflects things that are important to them.	All Surveys
		The proportion of families who report that staff who assist with planning are knowledgeable and respectful.	All Surveys
Choice & Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.	The proportion of families reporting that they control their own budgets/supports (i.e. they choose what supports/goods to purchase).	Children & Adult Family Surveys
		The proportion of families who report they choose, hire and manage their service/support providers.	All Surveys
		The proportion of families who report that staff are respectful of their choices and decisions.	All Surveys
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.	The proportion of eligible families who report having access to an adequate array of services and supports.	All Surveys
		The proportion of families who report that services/supports are available when needed, even in a crisis.	All Surveys
		The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication .	All Surveys
		The proportion of families who report that service and support staff/providers are available and capable of meeting family needs.	All Surveys
		The proportion of families who report that services/supports are flexible to meet their changing needs.	All Surveys
		The proportion of families who indicate that services/supports provided outside of the home (e.g., day/employment, residential services) are done so in a safe and healthy environment.	Both Adult Surveys
Community Connections	Families/family members use integrated community services and participate in everyday community activities.	The proportion of families/family members who participate in integrated activities in their communities.	All Surveys
		The proportion of families who report they are supported in utilizing natural supports in their communities (e.g., family, friends, neighbors, churches, colleges, recreational services).	All Surveys
Family Involvement	Families maintain connections with family members not living at home.	The proportion of families/guardians of individuals not living at home who report the extent to which the system supports continuing family involvement.	Family/Guardian Survey
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.	The proportion of families who report satisfaction with the information and supports received, and with the planning, decision-making, and grievance processes.	All Surveys
Family Outcomes	Individual and family supports make a positive difference in the lives of families.	The proportion of families who feel that services and supports have helped them to better care for their family member living at home.	Children & Adult Family Surveys

### ***Description of the Family Guardian Survey***

The Family Guardian Survey is administered to families and/or guardians of individuals who live outside of the family home. The survey asks families to express their overall level of satisfaction with services and supports their family member receives, as well as probes specific aspects of the service system's effectiveness. Along with demographic information, the survey includes questions related to: the planning for services and supports; access to and delivery of services and supports; choice in and control over supports; connections with the community; and satisfaction and outcomes. Combined, this information provides an overall picture of family satisfaction.

- ♦ Demographics – The survey instrument begins with a series of questions tied to characteristics of the family member with disabilities (e.g., individual's gender, age, race, type and level of disability), followed by questions pertaining to the respondent (e.g., respondent's age, relationship to individual, guardianship and frequency of visits with family member).
- ♦ Services Received – This section of the survey asks respondents to identify the services and supports their family member receives.
- ♦ Service Planning, Delivery & Outcomes – The survey contains several groupings of questions that probe specific areas of quality service provision (information and planning, access to and delivery of services, choice and control, community connections, satisfaction and outcomes). Each question is constructed so that the respondent can select from three possible responses ("always or usually", "sometimes", and "seldom or never"). Respondents also have the option to indicate that they don't know the answer to a question, or that the question is not applicable.
- ♦ Additional Comments – Finally, the survey provides an opportunity for respondents to make additional open-ended comments concerning their family member's participation in and experiences with the service system.

### ***NCI Recommended Sampling & Administration***

NCI recommends that states administer the Family Guardian Survey by selecting a random sample of 1,000 families who: a) have an adult family member with developmental disabilities living at home, and b) receive service coordination/case management and at least one additional "direct" service or support. Adults are defined as individuals with disabilities age 18 or older. A sample size of 1,000 is selected in anticipation that states obtain at least a 40% return rate, yielding 400 or more usable responses per state. With 400 usable responses per state, the results may be compared across states within a confidence level of +10%. In states where there were fewer than 1,000 potential respondent families, surveys are sent to all eligible families.

### ***Sampling Methodology\****

\* Information in this section is summarized from an earlier XenologiX report.

Xenologix developed a sampling plan to conduct the NCI Consumer Survey, and then targeted the families of these individuals to develop a sampling plan for the two NCI Family

Surveys. Below, brief descriptions of both the consumer and family sampling plans are provided:

The Bay Area Pilot Project is focused on assessing the quality of services and supports provided to consumers who are 18 years of age or older, and served by one of the three local regional centers. These individuals include those receiving Medicaid Waiver funding, as well as individuals who have transitioned from Agnews Developmental Center to home and community-based services.

NCI parameters require conducting a minimum of 400 in-person interviews for the Consumer Survey. The XenologiX study parameters dictated that the results be analyzed across the regional centers. Therefore, a larger sample would be needed. For participation in the Consumer Survey, a census to include 100% of the population of consumers who transitioned to the community was targeted. For the population of consumers who receive Medicaid Waiver funding, a random sample was drawn and provided by DDS. The DDS sample contained key contact information, including consumer and parent/guardian names, addresses, type of residence, and primary language. After receiving the sample records, XenologiX “cleaned” the sample, removing all invalid records. For the purpose of this study, invalid was defined as records where the address provided was insufficient for mailing or where the consumer’s status with the regional center was inactive, closed, deceased, or transferred.

The random sample was designed to assure a 95% confidence interval (i.e.,  $\pm 5\%$  margin of error). This included the overage required to compensate for invalid contact information and refusals to participate. For both sample populations, regional center staff obtained consent from the consumer or legal guardian to release consumer contact information to XenologiX. The original sampling plan was later revised to a sampling plan with a 90% confidence interval and  $\pm 10\%$  margin of error due to timeline/workload issues encountered.

The chart below details the populations served by each of the participating regional centers, the sample size pulled for each population segment, the consumer interview/family survey consents received, and the number of interviews required for each confidence interval.

Regional Center	Population Served	Sample	Consents	Interviews (95%)	Interviews (90%)
GGRC					
• Medicaid Waiver, 18+	2,039	588	277	377	221
• Consumers transitioned	11				
RCEB					
• Medicaid Waiver, 18+	3,349	691	312	414	249
• Consumers transitioned	11				
SARC					
• Medicaid Waiver, 18+	2,513	798	304	397	243
• Consumers transitioned	42				
	<b>TOTAL</b>				
• Medicaid Waiver, 18+	<b>7,901</b>	<b>2,077</b>	<b>893</b>	<b>1,188</b>	<b>713</b>
• Consumers transitioned	<b>64</b>				

The sampling plan developed for the Consumer Survey was also utilized for the two NCI Family Surveys (Adult Family Survey, Family Guardian Survey). The family surveys, however, targeted the family members and guardians of consumers, rather than the consumers themselves as respondents. XenologiX's target number of completions for the family surveys, combined, was 400. (Please note: NCI actually recommends a target number of 400 completed surveys for EACH survey. That is, NCI recommends submission of 400 Adult Family Surveys, and 400 Family Guardian Surveys). The following chart provides, for each of the three regional centers, a summary of the sample records received, and then details the number and type of surveys disseminated per regional center.

<b>Table 4</b>				
	<b>GGRC</b>	<b>RCEB</b>	<b>SARC</b>	<b>Total</b>
DDS Records Received	527	687	798	2,012
Invalid Records	2	4	6	12
= Valid Records	525	683	792	2,000
Adult Family Survey (English)	191	242	259	692
Adult Family Survey (Spanish)	25	25	13	85
Family Guardian Survey (English)	306	420	465	1,191
Family Guardian Survey (Spanish)	3	8	21	32
<b>Total Mailing</b>	<b>525</b>	<b>683</b>	<b>792</b>	<b>2,000</b>

### ***Data Collection Methodology\****

\* Information in this section is summarized from an earlier XenologiX report.

Each of the three regional centers was provided a sample introduction (pre-notification) letter for the Family Guardian Survey, which they could modify to accompany the survey. The letter described the survey's purpose and encouraged families to respond.

Letters and Family Guardian Surveys were mailed to 1,223 families (in the family's preferred language), along with a postage-paid, return envelope. Survey envelopes were stuffed by The Arc of Ventura County, based on instructions provided by XenologiX. The mailings were sent in several distributions during July 2005, and responses were received until XenologiX's target number was reached in October 2005.

### ***Data Analysis***

XenologiX's target number of survey completions (for both the Adult Family and Family Guardian Surveys) was 400. XenologiX received 431 responses. After data cleaning by XenologiX, it was determined that 396 of the responses were usable. Target completions by regional center were not established due to the relatively small number of total responses targeted and the number of surveys that were found invalid.

HSRI received from XenologiX Year One data that included 200 responses to the Adult Family Survey and 196 responses to the Family Guardian Survey, totaling 396 survey responses. Further data cleaning of the Family Guardian Survey responses by HSRI

staff determined that 192 of the 196 submitted responses were valid for analysis. HSRI personnel “clean data” (i.e., exclude invalid responses) based on four criteria:

- ♦ The question "Does your family member live at home with you?" was used to screen out respondents who received a survey by mistake. For instance, if a respondent indicated that their family member with disabilities lived in the family home, yet received the Family Guardian Survey, their responses were dropped.
- ♦ If the respondent indicated that their family member with disabilities was under the age of 18, their responses were dropped.
- ♦ If the respondent indicates that no services other than case management are received, their responses are dropped. Four (4) Bay Area Regional Center survey responses were dropped for this reason.
- ♦ If demographic information was entered into the file, but no survey questions were answered, these responses were also dropped.

In the Year One data, it is unknown which responses are from consumers who transitioned to the community and which are from Medicaid Waiver recipients. Thus, this data is presented in aggregate form.

NCI data management and analysis is coordinated by Human Services Research Institute (HSRI). Data is entered by each state/local authority, and files are submitted to HSRI for analysis. All data is reviewed for completeness and compliance with standard NCI formats. The data files are cleaned and merged, and invalid responses are eliminated. HSRI utilizes SPSS (v. 14) software for statistical analysis and N6 software for support in analysis of open-ended comments.

### III. RESULTS

This section summarizes the findings from the Family Guardian Survey. Please note that the tables provide results for the Bay Area Regional Centers (Year 1 data includes Medicaid Waiver recipients and consumers who transitioned to the community), plus state average results:

1. **Bay Area Regional Centers (“BARC”) Data** indicate the numbers and percentages across all three bay area regional centers.
2. **State Averages** indicate the numbers and average percentages across the other six states and one local DD authority that conducted this survey in 2005. They include Arizona, Connecticut, Hawaii, Pennsylvania, South Carolina, Wyoming, and Orange County Regional Center in California.

No statistical comparisons have been made between national and bay area results. The national data provided in the following tables and charts is solely provided for reference.

### ***Characteristics of Family Members with Disabilities***

The table on the following page provides information about the individual with disabilities living outside the family home.

Characteristics of Family Member with a Disability			
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)		NCI State Average (7 Sites)
Number of surveys	192		
	n	%	%
Gender:			
Male	104	57.8	55.0
Female	76	42.2	45.0
	180		
Age:			
Mean	39.1		44.0
Range	18-64		18-86
Type of Residence			
Specialized MR Facility	13	7.0	9.5
Group Home	127	68.3	59.4
Agency-Owned	6	3.2	4.3
Own Home/Apartment	32	17.2	10.9
Adult Foster Care/Host Family	5	2.7	11.0
Nursing Home	1	0.5	1.4
Other	2	1.1	3.4
	186		
Level of MR:			
No MR label	16	8.6	2.6
Mild	39	21.1	17.7
Moderate	57	30.8	29.8
Severe	35	18.9	22.1
Profound	6	3.2	11.8
Don't know	32	17.3	16.0
	185		
Race/Ethnicity* (duplicated counts):			
White	154	81.5	78.7
Black/African-American	7	3.7	5.3
Asian	15	7.9	9.1
American Indian/ Alaska Native	5	2.6	3.0
Hawaiian/Pacific Islander	2	1.1	2.6
Hispanic	10	5.3	3.5
Mixed Races	7	3.7	4.1
Other/Unknown	1	0.5	1.0
Other disabilities* (duplicated counts):			
Mental illness	27	15.4	19.6
Autism	41	23.4	9.9
Cerebral Palsy	36	20.6	17.1
Brain injury	13	7.4	10.1
Seizure disorder/ neurological	39	22.3	28.8
Chemical dependency	2	1.1	1.0
Vision or hearing impairments	30	17.1	22.8
Physical disability	33	18.9	25.2
Communication disorder	36	20.6	18.4
Alzheimer's disease	1	0.6	1.2
Down Syndrome	26	14.9	14.2
Other disability	25	14.3	15.4

## Characteristics of Respondents

The following table provides information about survey respondents. Respondents are the family members who completed the survey forms, not the individual with disabilities who lives outside the family's home.

Characteristics of Respondents			
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)		NCI State Average (7 Sites)
Number of surveys	192		
Age of Respondent:			
	n	%	%
Under 35	2	1.0	2.5
35 - 54	24	12.6	24.5
55 - 74	110	57.6	52.0
75 and Over	55	28.8	21.0
	191		
Relationship to Family Member:			
Parent	177	93.7	58.3
Sibling	7	3.7	22.0
Spouse	0	0.0	0.1
Other	5	2.6	19.6
	189		
If other relationship, please specify			
Grandparent	1	25.0	Not Available
Step-parent	1	25.0	
Self	1	25.0	
Uncle	1	25.0	
Sister-in-law	0	0.0	
	4		
Respondent is guardian or conservator:			
Yes	100	54.9	71.3
No	82	45.4	28.7
	182		
Frequency of Visits with Family Member:			
Less than once/year	7	3.7	4.7
1-3 times/year	23	12.2	12.6
4-6 times/year	20	10.6	13.4
7-12 times/year	23	12.2	13.0
More than 12 times/year	116	61.4	56.4
	189		



## Services and Supports Received

The table below provides information about the services and supports (other than service coordination) that the adults with developmental disabilities receive.

Services & Supports Received			
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)		NCI State Average (7 Sites)
Number of surveys	192		
Residential Supports			
	n	%	%
Yes	183	98.4	96.0
No	3	1.6	4.0
	186		
Day/Employment Supports			
Yes	167	91.3	86.6
No	16	8.7	13.4
	183		
Transportation			
Yes	160	87.9	93.5
No	22	12.1	6.5
	182		
Other Services/Supports			
Yes	82	50.3	69.9
No	81	49.7	30.1
	163		

### ***National Core Indicators***

On the next several pages, the questions and results are discussed that tie directly to the National Core Indicator domains for assessing service and support quality. These questions are grouped as they pertain to 1) information and planning; 2) access and delivery of services and supports; 3) choice and control; 4) community connections; and 5) overall satisfaction and outcomes.

For each domain and question, a Table is provided. The Tables detail results, by domain, for the Bay Area Regional Centers (Year 1 data includes both Medicaid Waiver recipients and Consumers who transitioned to the community), and the state/local DD authority average (i.e., the average percentage of the state-by-state results) for other NCI sites participating in this survey. Appendix A contains charts that detail the same information in a question-by-question format.

## Information and Planning

Information and Planning		
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)	NCI State Average (7 Sites)
Q1 - Do you get enough information to help you participate in planning services for your family member?		
Number of surveys	178	
% always or usually	64.6	76.2
% sometimes	25.3	17.8
% seldom or never	10.1	5.9
Q2 - If your family member has a service plan, did you help develop the plan?		
Number of surveys	143	
% always or usually	62.9	64.0
% sometimes	21.7	22.1
% seldom or never	15.4	13.9
Q3 - If your family member has a service plan, does the plan include things that are important to you?		
Number of surveys	142	
% always or usually	76.8	78.7
% sometimes	19.0	17.8
% seldom or never	4.2	3.5
Q4 - Are the staff who assist you with planning generally respectful and courteous?		
Number of surveys	169	
% always or usually	92.3	92.9
% sometimes	5.3	6.2
% seldom or never	2.4	0.9
Q5 - Are the staff who assist you with planning generally effective?		
Number of surveys	158	
% always or usually	77.2	79.3
% sometimes	19.6	18.3
% seldom or never	3.2	2.4
Q6 - Can you contact the staff who assist you with planning whenever you want to?		
Number of surveys	168	
% always or usually	85.1	85.2
% sometimes	10.1	12.2
% seldom or never	4.8	2.6

## Access and Delivery of Services and Supports

Access and Delivery of Services and Supports		
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)	NCI State Average (7 Sites)
<b>Q7 - When you ask the service coordinator/case manager for assistance, does he/she help you get what you need?</b>		
Number of surveys	169	
% always or usually	80.5	82.9
% sometimes	14.8	15.0
% seldom or never	4.7	2.1
<b>Q8 - Does your family member get the services and supports he/she needs?</b>		
Number of surveys	179	
% always or usually	83.2	83.1
% sometimes	14.5	15.5
% seldom or never	2.2	1.4
<b>Q9 - If your family member does not speak English or uses a different way to communicate (e.g., sign language), are there enough support workers available who can communicate with him/her?</b>		
Number of surveys	52	
% always or usually	73.1	78.9
% sometimes	13.5	17.2
% seldom or never	13.5	4.0
<b>Q10 - Does your family member have access to the special equipment or accommodations that he/she needs (e.g., wheelchairs, ramps, communication boards)?</b>		
Number of surveys	69	
% always or usually	79.7	86.9
% sometimes	14.5	10.1
% seldom or never	5.8	3.0
<b>Q11 - Are frequent changes in support staff a problem for your family member?</b>		
Number of surveys	155	
% always or usually	12.9	22.0
% sometimes	47.7	46.2
% seldom or never	39.4	31.8
<b>Q12 - Do you feel that your family member's residential setting is a healthy and safe environment?</b>		
Number of surveys	183	
% always or usually	92.9	88.9
% sometimes	6.0	10.0
% seldom or never	1.1	1.1
<b>Q13 - Do you feel that your family member's day/employment setting is a healthy and safe</b>		
Number of surveys	161	
% always or usually	91.9	89.5
% sometimes	7.5	9.6
% seldom or never	0.6	0.9

## Choices and Control

Choices and Control		
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)	NCI State Average (7 Sites)
<b>Q14 - Does the agency providing residential services to your family member involve you in</b>		
Number of surveys	177	
% always or usually	75.7	78.6
% sometimes	16.9	16.1
% seldom or never	7.3	5.4
<b>Q15 - If your family member gets day or employment services, does the agency providing these services involve you in important decisions?</b>		
Number of surveys	143	
% always or usually	62.2	64.4
% sometimes	21.7	22.0
% seldom or never	16.1	13.6
<b>Q16 - Do you or your family member choose the support workers that work with your family?</b>		
Number of surveys	132	
% always or usually	20.5	21.4
% sometimes	12.1	13.6
% seldom or never	67.4	64.9
<b>Q17 - Do you or your family member have control and/or input over the hiring and management of your family member's support workers?</b>		
Number of surveys	135	
% always or usually	14.8	14.7
% sometimes	4.4	9.4
% seldom or never	80.7	76.0
<b>Q18 - Do you or your family member <u>want</u> to have control and/or input over the hiring and management of your support workers?</b>		
Number of surveys	121	
% always or usually	28.1	30.6
% sometimes	37.2	35.3
% seldom or never	34.7	34.1
<b>Q19 - Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?</b>		
Number of surveys	178	
% always or usually	35.4	31.0
% sometimes	9.6	12.7
% seldom or never	55.1	56.3
<b>Q20 - Do you or your family member get to decide how this money is spent?</b>		
Number of surveys	143	
% always or usually	28.0	25.5
% sometimes	18.2	26.2
% seldom or never	53.8	48.2

## Community Connections

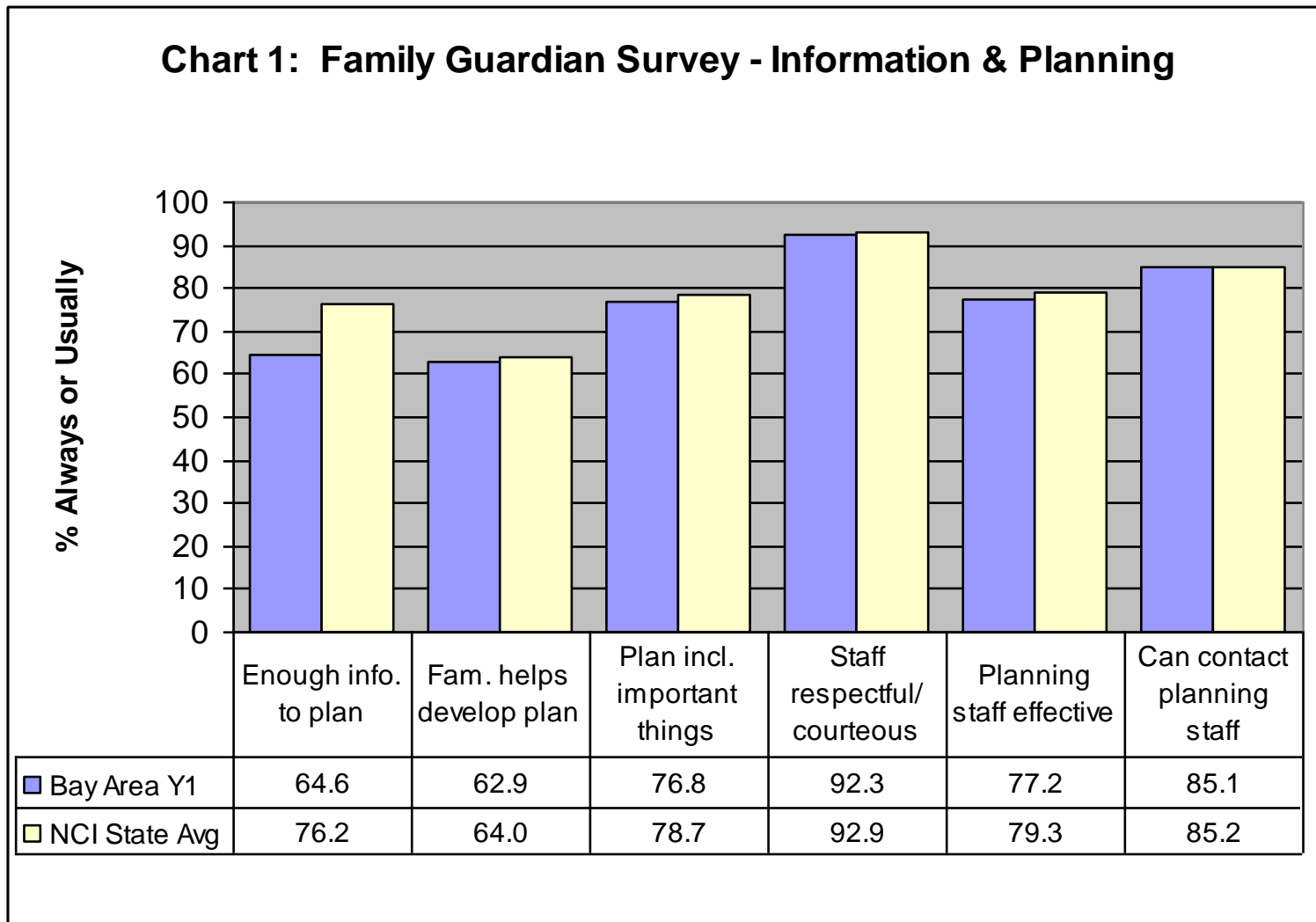
Community Connections		
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)	NCI State Average (7 Sites)
Q21 - If your family member wants to use typical supports in your community (e.g., through recreation departments or churches), do either the staff who help plan or who provide support help connect him/her to these supports?		
Number of surveys	115	
% always or usually	58.3	58.8
% sometimes	23.5	26.6
% seldom or never	18.3	14.6
Q22 - If your family member would like to use family, friends, or neighbors to provide some of the supports your family needs, do either the staff who help plan or who provide support help him/her		
Number of surveys	89	
% always or usually	61.8	59.0
% sometimes	22.5	22.4
% seldom or never	15.7	18.5
Q23 - Do you feel that your family member has access to community activities?		
Number of surveys	149	
% always or usually	61.1	65.5
% sometimes	26.2	26.5
% seldom or never	12.8	8.0
Q24 - Does your family member participate in community activities?		
Number of surveys	149	
% always or usually	37.6	43.8
% sometimes	40.3	40.7
% seldom or never	22.1	15.5

## Satisfaction with Services and Outcomes

Satisfaction with Services and Outcomes		
	Bay Area Regional Centers Year 1 (Medicaid Waiver and Consumers Transitioned to Community)	NCI State Average (7 Sites)
<b>Q25 - Overall, are you satisfied with the services and supports your family member currently</b>		
Number of surveys	181	
% yes or most of the time	79.6	83.8
% some of the time	18.8	14.8
% no or not at all	3.0	1.4
<b>Q26 - Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?</b>		
Number of surveys	164	
% yes or most of the time	51.2	55.8
% some of the time	6.7	8.7
% no or not at all	42.1	35.5
<b>Q27 - Are you satisfied with the way complaints/grievances are handled and resolved?</b>		
Number of surveys	94	
% yes or most of the time	70.2	67.6
% some of the time	20.2	26.5
% no or not at all	9.6	5.9
<b>Q28 - Do you feel that services and supports have made a positive difference in the life of your</b>		
Number of surveys	178	
% yes or most of the time	84.8	85.1
% some of the time	14.0	13.6
% no or not at all	1.1	1.3
<b>Q29 - Overall, do you feel that your family member is happy?</b>		
Number of surveys	180	
% yes or most of the time	83.3	82.6
% some of the time	16.7	16.1
% no or not at all	0.0	1.4

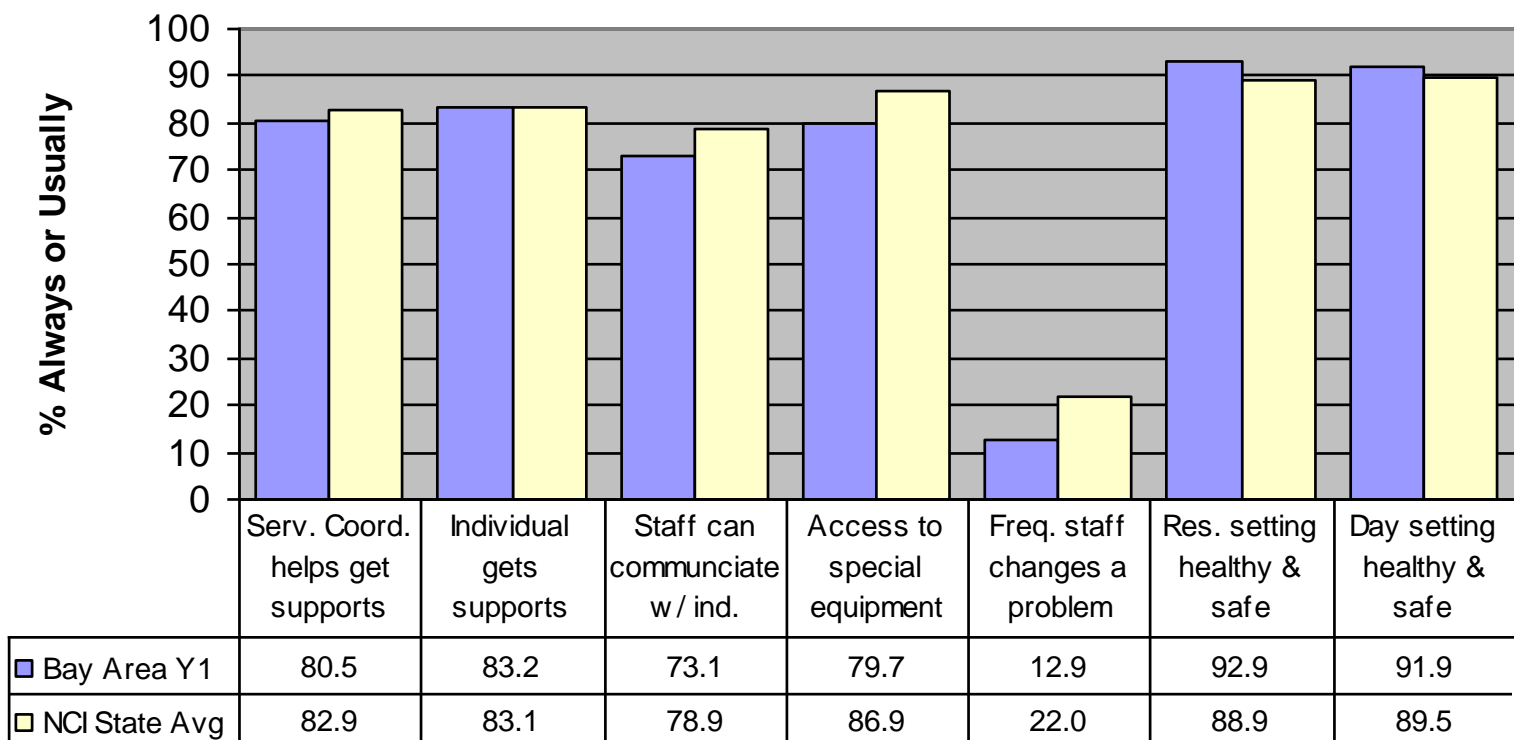
### Results by Domain Compared to Aggregate Results

Here, the Bay Area Regional Centers' results are presented by topic grouping, and compared against the state averages.

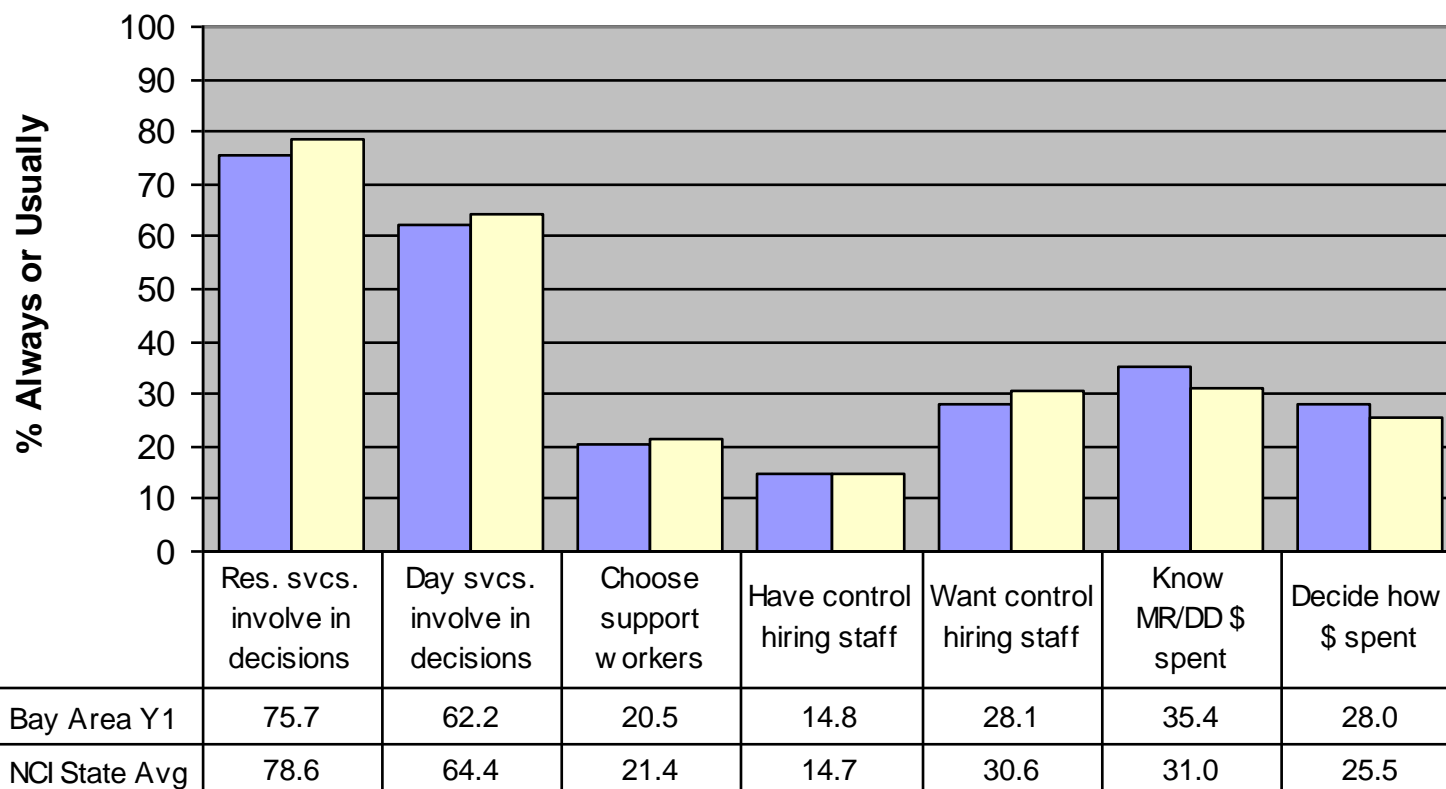




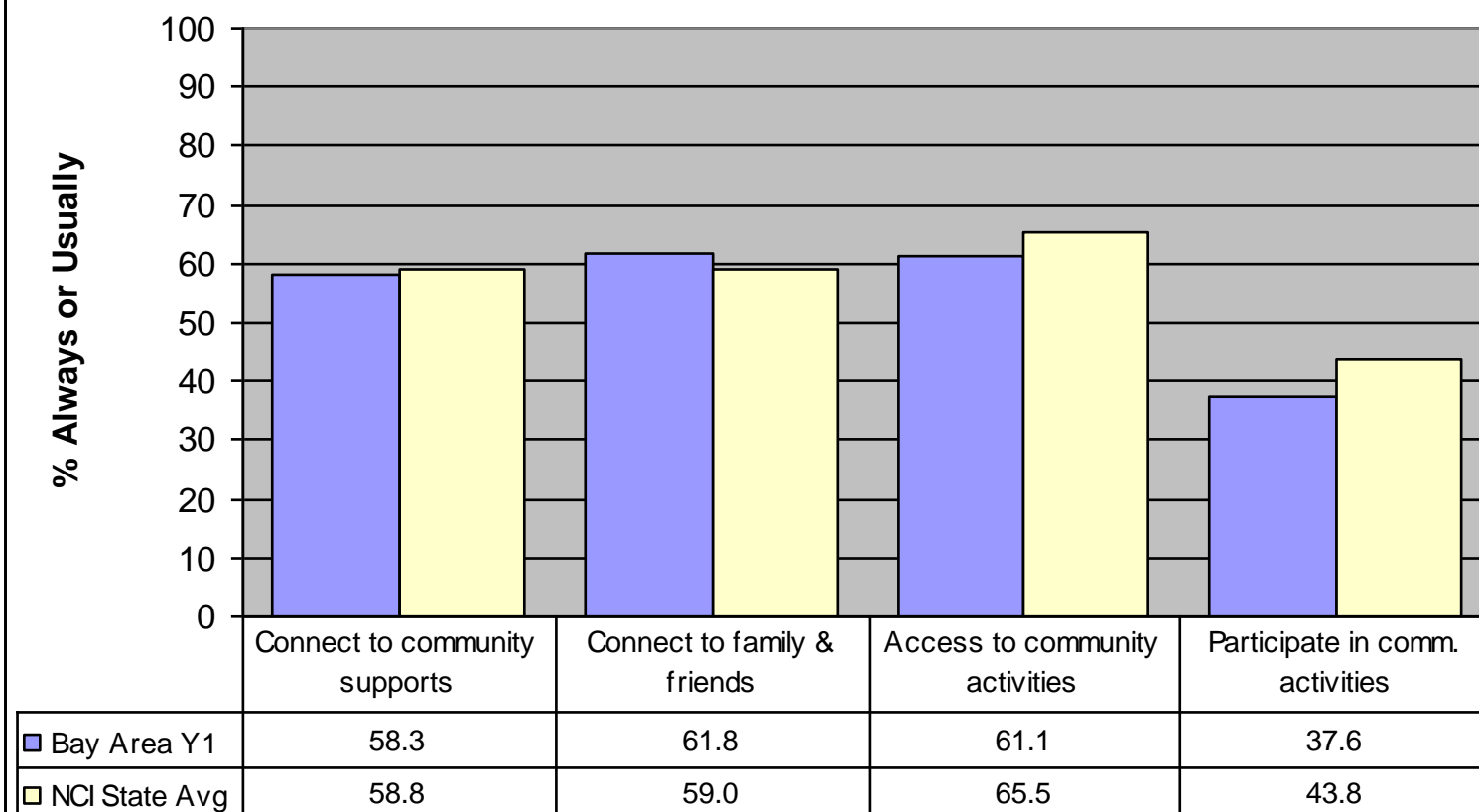
**Chart 2: Family Guardian Survey - Access to Services**



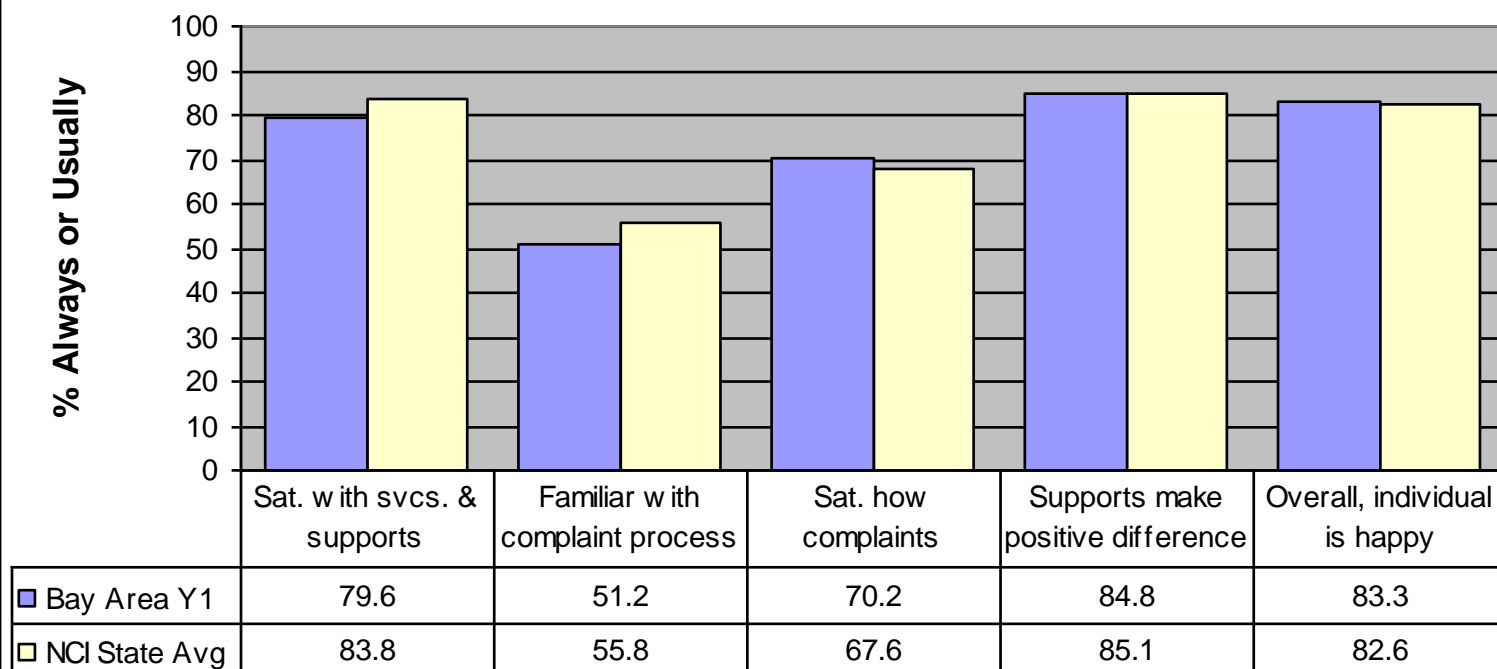
**Chart 3: Family Guardian Survey - Choice & Control**



**Chart 4: Family Guardian Survey - Community Connections**



**Chart 5: Family Guardian Survey - Satisfaction & Outcomes**



## IV. COMMENTS

In addition to the quantitative survey questions, there was a page at the end of the survey for respondents to record comments. All comments are included below, with identifying information removed. Where possible, they are categorized by regional center.

### ***San Andreas Regional Center***

- I am a little concerned that my son is on a drug that has negative side effects. It makes him feel exhausted all the time. I have documented evidence this can be an unsafe drug. I'm requesting the psychiatrist to lower the dosage to the smallest possible amt. My son's San Andreas counselor is not in agreement with this. I am in the process of trying to get medical conservatorship for him.
- Limited assistance from SARC social worker - or lack of motivation of work hinders the ability of my son to reach his potential as an adult. Feel worker underestimates the mental capacity my son has because of limited patience to wait for him to communicate via outdated technology. Worker has not been supportive in helping to acquire new technology device for daily communication.
- We are well pleased with the placement, and oversight provided by the San Andreas Regional Center, for [our son]. We are overwhelmed by the care and love that he receives at the home. It is truly a blessing for him and ourselves.
- Our daughter is in supported living. In the 11 years since she left Stockton Developmental Center, her agency has worked tirelessly and very effectively to address all of the problems that confront her. I am so grateful that she is with this agency and that we in the San Andreas Regional Center catchment area. This regional center is the very best. A grateful parent and conservator.
- San Andreas support has been wonderful. Thank you.

### ***Golden Gate Regional Center***

- Best of thanks for the Executive Director and staff of Golden Gate Regional Center for this survey and the efforts they made on ground of improving and continuation of services to people with disabilities
- This survey is far too long and the questions are repetitive and some are confusing. We are happy with the services provided by GGRC.
- Very frankly most of Golden Gate Regional case workers are nothing more than paper pushers. The last time I visited the San Rafael office, the receptionist could scarcely separate her attention from her computer screen long enough to acknowledge our presence - and no wonder! As I glanced at her screen, she was playing poker!!
- I've been very happy with the services of the Golden Gate Regional Center.
- Right now we are very unsatisfied with the group home our son is in. It was taken over and is run by new people. The Golden Gate Regional Center, Marin County, California is looking for a better placement, however and is trying to get improvements at the home in the interim. It is the man who runs the group home and a few of his employees who are the problem.

- Current Golden Gate Regional Center caseworker is excellent. Before son moved to group home, frequent changes of caseworker was a problem. Also caseworker did not seem to be knowledgeable in how to begin search for group home/apt. and refer us to inappropriate situations.

### ***Regional Center of the East Bay***

- The dedication case managers like ours bring to their jobs is amazing. The work load and the effort brought forth by her marks a special person in my book. To genuinely like and care for the welfare of disabled individuals as she does daily is no easy task. In organizations that directly care for these individuals, the care providing agencies, the services are generally good but can be spotty. This can be due to rapid turnover of individuals and/or lack of true understanding (sometimes maturity) of their function. RCEB performs well with a minimum of state support and under demanding circumstances. I applaud their efforts and I am happy they are there
- General Comments: 1) We are not fans of RCEB. 2) Letter with the questionnaire from RCEB is dated June 15, and we received it on Aug 2nd. Typical of RCEB. Actually we are surprised we even got it at all. This is the first piece of literature we have received from RCEB in many years.
- It would be appreciated if client could have her evaluations in September when we are in her area. It would be appreciated if when a new case worker takes over we would be notified. It would be greatly appreciated if case worker would contact us after any meeting with client, or any evaluation takes place. We would like to be informed of any new plans case worker or RCEB has for our daughter. Would like our daughter be associated in a group home with another of her ability. I think it's necessary for her to have a close friend. Also when she arrives to her group home there is not anything for her to do except spend most of the time in her bedroom. Also Sat & Sun most of the time her time is spent again in her bedroom. She may prefer this but don't believe it's a happy atmosphere for her.
- My daughter's case manager was completely ineffective at providing resources for housing and day programming. 2) RCEB appears to be more concerned about resource (funding) management than program development (life enhancement). Please don't hesitate to call...
- I'm not sure how much input this is supposed to be an "independent living" program for my daughter. I try to stay out of things, but sometimes I need to know what is going on, and find it hard to get answers from the IL agency. I never have problems getting answers from her RCEB caseworker. She's wonderful!
- Good group homes are hard to find. It's hard for providers. Despite some problems and crises, we've been fortunate. And we appreciate RCEB and our case worker.
- I am particularly pleased and grateful for the services rendered by [provider]. The regional center, under the present case manager, has also been exemplary. A previous case manager had serious character problems.

### ***Non-Specified Regional Center***

- [Name] is an extraordinary social worker. Deserves awards!

- We would appreciate that the people running the board and care facility that our family member lives in be instructed to call us before bringing our family member for a visit. They usually have him call, but that is not sufficient because he'll just tell them that it's okay for him to come over; whether it is or not. We really need the person in charge to call before and visit as we are getting older and have a lot of health problems.
- My daughter was made a ward of the court...when she was four years old. Later she was placed in a home where we visited her fairly regularly. After a while she was moved to another home- we were never sure why and we went overseas for almost two years. From that time on we never saw her or had any contact with her. On occasion we would receive some minor news from the Regional Center. In the meantime we had had three other children and that + work + work overseas meant no contact at all. A number of years ago one of my daughters attempted to make contact, did see her and take her out of out occasionally but had to stop because it wasn't working out. She was working, had children of her own and unless she saw her sister weekly or more often she was not recognized. I guess this is a sad but common story. I'm not sure how helpful my answers are since I have no knowledge at all of what is happening.
- She has just moved to this care home - she seems to be adjusting well and the home is great at communicating with me (her mother) so far I am very very pleased with her new placement. She has started day program and seems to like it. She is out in the community quite a lot and loves it.
- My daughter has moved to this group home in April. We have not had an IPP at the home. Have had two at her day program. Was assigned a case worker about one month ago. I believe there will be a group home meeting soon. I hope. I will have to make sure this will occur.
- The last bit of correspondence I received from the Regional Center was approximately a decade ago. My son and I were never real close so it isn't surprising I don't know some of the answers. He's a grown man now and I don't keep in touch as much as I should.
- We saw her regularly when we were all younger. She is now in her 60's and we, her parents, are in our mid-80's. We exchange pictures and I talk with [care provider] on the phone to see if she needs anything we can send her. We saw her last in 2000 when her sister came West and we all drove up to take her to supper. Please excuse writing. My vision is going.
- I have tried to visit him once a month if possible. This year has been bad for me. I have a sprained back and can't drive far, also for the price of gas now it's hard to do. I wish I could come more. He has access to mental health care. I would like him to have more speech therapy. I don't interfere with management plans. They don't ask or discuss plans with me. They are usually doing a good job.
- Until the last two years I was able to visit him once or twice a month, but due to his placement in another city and my advanced age and health problems I have been unable to see him. I talk to his caretaker and she has been very good about letting me know of any health problems he is experiencing.
- It was very difficult to answer in any of the questions as my son lives up North and I live in Southern California. From the observations that I have made, the services he receives are very supportive.
- I think that the Regional Center needs to pay more attention to the counselors and the agents that try to separate a child from their natural parent that is involved with their

child. They waste too much time on the "18", a child can make their own decision. If a child is mentally retarded, can't speak, can't write and no comprehension, they cannot make their own decision. The program needs a lot of re-vamping. I am very capable to make decisions but my mother, even at my age of 54 years still helped me make decisions until she passed away. I don't think it's right when you try to separate a parent and a child that love each other.

- Terribly over-weight - 300 pounds!!! Unhealthy. My son has a paid, live-in room mate, but the place is unhealthy to live in - also filthy. Was recently (July\_ there to visit with his out-of-town uncle who is a minister and was totally embarrassed and disgusted by the filthy apartment my son and his roommate live in. Carpets look like they haven't been cleaned in four years. Lots of paper clutter, fire hazard everywhere! Uncle questioned roommate on his job description. Vacuum wasn't working. They've been sweeping clutter around clutter/debris with a broom. Nothing was wrong with the vacuum - just clogged. My husband unclogged it (took 15 mins) on the spot. Paid help is too lazy or inept to do/teach basic household fixes, such as this. Same thing repeatedly. They should learn how. It's the blind leading the blind. Excessive-compulsive collecting of recyclables/trash. Been there a very long time. Excessive smoking. Burns on furniture. Broken...-unsafe. Full ash trays.
- I wish my family member who is high very functioning was required to do some kind of work or activity to give back to the community for the help and support my family member receives. Sometimes rules of conduct for visitors need closer reinforcement. Clients need support in decision making over emotional issues. Get taken advantage of easily. My family member has been given good services and support by her mentors, etc.
- I am (his) mother. His sister...has been appointed conservator since his father's death...I do not drive and am crippled with arthritis, but his sister takes care of his needs whenever necessary. He loves to visit for a day between 1-4 times a year.
- I feel very satisfied with this place.... Because is clean and safe; I like the staff members especially because they are females.
- A few years ago a psychiatrist tried Prozac on him. I felt it was not needed as generally he is fairly docile. I made no difference in his behavior.
- I have recently entered a nursing home (ca. 1 yr). A good friend serves as my representative at IPP mtgs, queries and interactions with my daughter.
- Our son was scheduled for a free-of-charge dental exam and oral surgery. He moved just before the scheduled surgery. We had cancelled it, expecting him to get similar services closer to his new home. It has not happened yet. His mouth now bleeds when he brushes that is due to the impacted bicuspid. When our son visits, every other weekend, he attends church services and goes on many main stream community outings. He sometimes visits with family (extended) as well. He was at his cousins wedding recently, for instance. A lot less of that goes on during the week and on the weekends he is not with us. But I understand that his home is making a concerted effort to improve that situation.
- In the past 2 years there has been minimal contact with my son's case manager at meetings held between case manager and residence wasn't informing me and non-attendance by case manager at work site scheduled meetings. Very unsatisfactory participation/communication with regional center representative in past two years.



Thankfully, we've not had any crisis in this time, or that how one gets communication from case manager?

- Overall our daughter has received very good care. She has always seemed happy when we visit her. We regret that because of the distance and our ages over visits have not been as often as we would like. She is profoundly retarded, can't speak or walk. There are some planned activities at centers at which she participates to a very limited extent. Last time I asked she was not toilet trained except occasionally. She appears to be pleased with the lady taking care of her but doesn't recognize us. My husband has developed Parkinson's disease which makes driving problematical for him and I have been turned down once for a license which was finally given me after some eye treatment. Renewal may not be possible. Our daughter is much happier in this small care center with more personal care than she was in the hospital situation.
- On a whole I am satisfied with the group home my son is in. I do have some concern when I call and can't understand the person I am talking with and they can't give me the information I am requesting. If I can't understand them, how can my son?
- Since I live far away, I do not have much contact with my son and his care givers. I phone him periodically, but it is a one-way street - never phones me. The caregiver does have my phone number.
- Barriers affecting my son's quality of life -
  - \* Scarcity of qualified people to work with my son at the low wages that are offered through IHSS
  - \* High turn-over of staff (low wages and lack of good benefits does not encourage people to make this work their career or long term commitment)
  - \* High cost of living where he's living makes it difficult for him to find affordable living on his SSI benefits
  - \* Local regional center's policy that facilitated communication is experimental and they will not fund staff training to support my son's communication over the past 12 years has added additional challenges to both my son's and my life.
- My son lives in a group home and attends a day program. I was very involved in the choice of the group home and the day program, but have nothing to do with hiring, choosing, etc., support staff at either place or with who his Regional Center worker is so I marked N/A on Q16-18.
- Underwear and clothes get mixed up with other residents' at times. Either they are not proper fit or other underwear/socks should not be used. 2) Teeth brushing or least gargle with LISTERINE before going to bed will be good practice for teeth health. 3) Emphasize to make it a habit to clean after using toilet and wash hands always after that.
- Thanks for giving me the opportunity to give my opinion. This is the first time this has occurred.
- Funding should go towards counseling/community service - follow through on IPP. What happens when IPP is not happening?
- Turn over of staff is always a potential problem, to your credit you have selected quality people to support my daughter...she is very important to me. I can go to sleep knowing that my child (40 a child??) is being cared for in the manner I would give her. I salute you for an outstanding job. Any questions or concerns have been handled to my satisfaction. I also thank you. Thank you. Thank you. Thanks!

- The Philippine people who operate board and care homes brought caring and stability into my daughter's life. I am grateful to them and the regional center.
- She has been in the same group home for about 5 years and is very much a part of a family. She goes to workshop which she enjoys. We see her almost every weekend for an outing. The group home arranges many outings for their clients. She has a rich life. The group home is owned and operated by ... We couldn't wish for a better placement.
- My son died July 2005 - I felt I needed to fill out this form so you can get the feedback data. Overall I was very happy with his placement and the Regional Center was wonderful. Thank you so much.
- I am very satisfied at present. We have a good house manager and an excellent relief. In the past, we have had difficulty getting a steady manager but [name] has been there for 2+ years and before that [name] was also there for 2+ years. It is difficult when the clients have to adjust to three different staff in a week but I know help is difficult to find at the wages the State allows. So right now, we're OK.
- My daughter is in a wonderful home. Of the 4 homes she has been in, 3 were excellent; 1 was not as good. You are doing a great job with services.
- The people who "service" my family members are usually overburdened and overworked with too many clients
- [Names] are loving, caring & knowledgeable care providers. I do not know who at the Regional Center has any input or control in my daughter's lives but as long as they are with [providers] I am happy. [Names] have grown and seem very happy with their group home and that is most important to me.
- [Provider] is best in state. Get the state to give more money to the Regional Centers then on the agencies.
- We feel very fortunate to be living in CA with all the support that is available. Our son has a wonderful and fulfilling life - more than we could have hoped for - he is supported by a wonderful staff who are devoted and truly caring individuals. We have had nothing but positive experiences!
- My son's caseworker is wonderful!!
- Great organization
- Our case manager is the best case manager we have ever had. She goes out of her way to make sure that her needs are being met and always has her best interests in mind. We are thankful to have our case worker - she is an amazing and caring case manager and a family friend!
- Thank you very much for your services and concern.
- I feel that my son is in a wonderful, clean, caring, environment. I am happy with his care.
- I have two problems that are difficult to resolve, but would appreciate it if these items could be addressed: 1) Over the counter medicines may NOT be brought into a facility. I don't see a problem if the seal is not broken on them but evidently regulations will not allow it. Case in point is Benefiber. Costco has a very good price on a large bottle but does not put a pharmacy label on it and thus the facility will not accept it. They are required to have a pharmacy label on all medications. This puts undo cost on the

residents. 2) My daughter was previously a resident at Agnews. Community medical appointments have, at times, been a disappointment. The staff at Agnews knows how to handle a client such as my daughter. Her GYN appt was in the community and was attempted by a physician that was pregnant. My daughter is combative so the physician was very hesitant to examine her. A brief exam was done and a PAP was obtained but under very traumatizing circumstances. The physician at Agnews along with his staff are much more prepared to deal with clients of this nature and also in a more speedy manner. I would that access thru the KOFT initiative would become available to serve DD clients.

- Very satisfied!
- Their computers cannot get my name correct!
- Our son has been extremely happy in his group home and work placement. As an only child, the group home has helped his social growth. For the first time, he has "brothers and sisters" and he is learning how to share and get along with others (taking turns, etc.). We have been very impressed by his current social worker. She is professional, kind, understanding, and helpful to us as a family. She certainly represents the best her peers. We feel fortunate to have her in our lives.
- We are very grateful for the group home care our son gets, and day program. He feels useful as they try to allow him to do things. Day program lets him help and sets him up with his "books on tape" and occasional trips/ He gets good care at his group home. He comes home often and ready for family events. He is always well groomed and dressed. He loves it when they let him participate in cooking meals, joining them while they are cooking. He feels helpful then. He gets use of the van for their outings and enjoys that. He enjoys borrowing videos and DVDs to watch at the group house. We love that he is close to home, too, for often visits. Thank you for all of your help and guidance.
- Thank you for all that you do!
- We are very pleased with the over all care our daughter has received.
- I am very happy with the way xxx has handled the entire situation and with loving care.
- She is very happy in her group home. She is always well groomed and very clean. Her speech is difficult to understand but her caretakers take time to understand her. She has had problems with her medication since leaving Agnews and the staff at her group home have been very helpful trying to find a remedy for this. Her social worker has been very helpful to me and to her. She has made my daughter's move so much easier for us all as have the staff at the group home.
- We are co-conservators and we agree to all answers to these questions. We found some questions are difficult to answer because our family member has resided in a residential facility for less than a year. Also, we answered Part 1-h with both of our ages. We would like to commend the developmental center liaison for finding an exceptional home and program for our family member's needs. She has also helped us develop the personal program needed.
- I have been very satisfied with my sisters' group home environment since she moved there two years ago. However, on recent visits she has seemed quieter and the house seems too full.
- Through the years I have been very satisfied with the placements and services my daughter has received, however, I feel an injustice is being done by the licensing for not

considering all the facts before denying a waiver for her to stay in her present home where she has lived for 13 years, being the first resident there just because she turned 60 this year and there are two people there, who came in years after she did, who are 60. She is very healthy and happy in her group home but she gets traumatized by any change, due to her illness. She sees a psychiatrist every month to help her cope and I feel she does not need additional problems, especially when the operator of the home is willing to keep her there.

- Would appreciate a more detailed (monthly) accounting of money (personal) spent.
- Q17. To date the staff assisting our son have been excellent.  
Q18. We would want consultation with changes, not control or management  
Q29. With the services provided, very happy. In life - his disabilities make socializing very difficult.
- I am his mother as well as his legal guardian. I am also the mother of five other children. He is the oldest of all. I really appreciate the help you all are giving him. Thanks!
- The residence staff are excellent and always available to answer any questions or concerns I have as a parent. I am not at every evaluation as I live in another state but have been pleased with plans. The group home situation for my son is very appropriate and I have an excellent working relationship with the owner/director.

## V. DISCUSSION

The results of the Family Guardian Survey provide one lens through which the Bay Area Leadership Group can assess the quality of Regional Center services and supports being provided to adults living in the community, from the perspective of the families and guardians of these individuals. This section presents a summary and discussion of findings by topic (domain) area, as well as specific process recommendations to be considered for future quality assurance survey activities. Where appropriate, observations regarding policy implications are also presented.

### ***Information and Planning***

Respondents generally gave high marks to the Regional Centers in the area of service planning. The vast majority of families and guardians who answered the survey felt that service coordinators were respectful, accessible, helpful, and effective. Approximately two-thirds of respondents reported that they participated in the development of their family member's service plan, and a higher percentage (about three-fourths) felt that the plan included things that were important to them. Most of the scores in this section were comparable to the findings in the 2005 NCI survey, which included data from six states plus the Regional Center of Orange County.

One exception is the question, "Do you get enough information to help you participate in planning services for your family member?" Only 65% of Bay Area respondents answered "always or usually" to this question, which is considerably lower than the NCI state average of 76%. Regional Centers may want to explore this issue further to

determine where the gaps are in the process and how facilitation of family involvement in planning could be improved.

### ***Access and Delivery of Services and Supports***

Overall the Regional Centers performed well in this area. Most respondents indicated that their family members have access to the services and supports they need. Over 90% of families and guardians who answered the survey feel that their family members' day and residential service settings are healthy and safe environments. These results were just slightly higher than the NCI comparison data. Bay Area respondents were somewhat less concerned about staff turnover, with only 13% describing changes in support staff as "always or usually" a problem, in contrast to 22% of NCI respondents.

Two items in this section were scored slightly lower than the comparison NCI survey data. The first is Question 9, which reads "If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?" Bay Area respondents were more than three times as likely (13.5% vs. 4%) to report that support workers who are able to communicate with their family members are "seldom or never" available. This is a critical finding; however it raises more questions than it answers. Are there enough bilingual support workers? Which languages are needed? Is English competency among staff a problem? Is there a need for greater access to assistive communication devices?

The communication issue warrants further exploration. In the future, the Regional Centers may want to separate Question 9 into two parts in order to better understand the policy implications for staff training and competency requirements.

The second finding that seemed to be slightly lower than the NCI norm was the response to the question, "Does your family member have access to the special equipment or accommodations that he/she needs?" Nearly 6% of Bay Area respondents answered "seldom or never" compared to 3% of NCI respondents. This is an important access issue that could be investigated further.

### ***Choices and Control***

According to families who responded to the mail survey, Bay Area providers typically involve families and guardians in making important decisions. Residential service providers involve families in decision-making more often than day service providers (76% "always or usually" do vs. 62%). Only about one-fifth of respondents report that they or their family members choose their support workers. Very few families (15%) report having any control or input over the hiring and management of support staff. However, 28% of respondents indicated that they or their family member would like to have control over the hiring and management of staff. Regional Centers may want to gather more information from families and individuals about the extent to which they would like to be involved in choosing their support staff. Do they want to employ their

own staff? Do they want to be more involved in the interview process? Since the survey question broadly asks about wanting more “control and/or input” it would be important to define more precisely what degree of involvement people would like to have and what the range of options should be.

In general the Bay Area findings in the area of choice and control are in line with the NCI data. Slightly higher percentages of Bay Area families report that they know how much money is allocated for services for their family member and that they decide how these funds are spent.

### ***Community Connections***

The first two items in this section ask about whether respondents feel their family member is connected to “typical” or generic supports in the community and whether the staff help to facilitate “natural supports” that could be provided by friends, neighbors, etc. The majority of families and guardians responded affirmatively to these questions, and their responses were similar to those in the NCI comparison data set.

The other two questions address the individual’s access to and participation in community-based activities. While the majority of families and guardians indicated that their family members “sometimes” or “always” have access to such activities, the percentages were slightly lower than the NCI norms. Perhaps the most striking result is that 22% reported that their family member “seldom or never” participates in community activities. These findings suggest that community participation would be an appropriate focus area for Regional Center quality improvement strategies.

### ***Satisfaction with Services and Outcomes***

Approximately 80% of families and guardians surveyed indicated that they are satisfied overall with the services and supports their family member receives. This is a typical result for a general satisfaction measure, which tends to yield a very high percentage of positive responses. Perhaps more importantly, nearly 85% answered that they “always or usually” feel that these services and supports have made a positive difference in their family’s life.

This section also included two questions about the process for filing complaints or grievances. A high percentage of respondents (42%) were not familiar with the process for filing a grievance related to services or staff. Of those who had gone through this process, most were satisfied with the results. It would appear from these findings that more education may be needed to ensure that families and guardians are aware of their rights and the avenues available to them for addressing and resolving problems.

### ***Process Recommendations***

Should the Bay Area QMS decide to administer this survey again, there are a few logistical points to consider. First, the Family Guardian Survey should only be sent to a

family member, or if there is no family contact, to a guardian, who has some contact with the individual. A few of the write-in comments suggested that the respondent was not presently involved in the person's life and therefore could not offer a meaningful assessment of the quality of services and supports being provided.

Another suggestion is to add a "waiver of confidentiality" at the bottom of the survey form, following the open-ended comments section, in order to give the respondent an option to sign the form and provide follow-up contact information. While most issues are resolved through typical channels (e.g., contacting a service coordinator), occasionally a family or guardian will identify a concern in the comments section that the Regional Center may not have been aware of. If no contact information is provided and confidentiality has not been waived, the Regional Center is not able to respond to the concern. In the Bay Area survey, clearly there were some comments describing situations where families may have needed assistance or information. By including this type of waiver, the Regional Center could use this tool as one additional way to remediate such situations.

Lastly, future iterations of this survey should include some way to code which Regional Center the response came from. The surveys could be color-coded, or the respondent could be asked to check off which Regional Center coordinates their services.

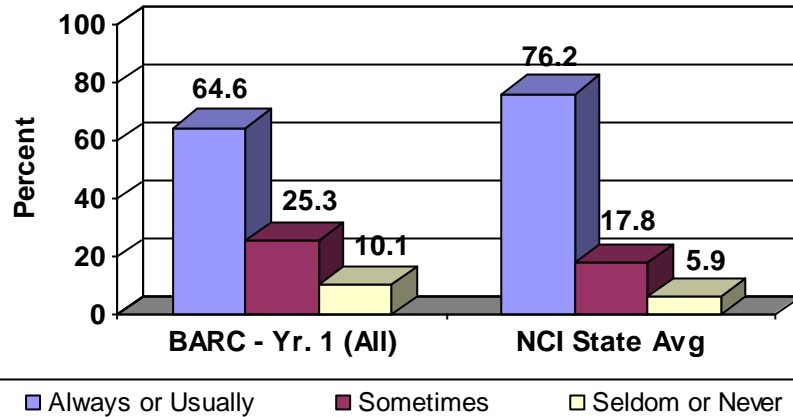
In conclusion, this activity was a major undertaking for the Bay Area Regional Centers, and they should be commended for their efforts to gather feedback from service users and their families. Positive results should be seen as confirming for Regional Center staff and management who are working every day to ensure that people and their families have the supports they need. The results also suggest some potential opportunities for improvement. Further discussion among leadership and with a variety of stakeholders will shed additional light on these areas of concern and hopefully generate ideas that will lead to the development and implementation of improvement strategies at a system level.

## **APPENDIX A: Charts of Results by Question**



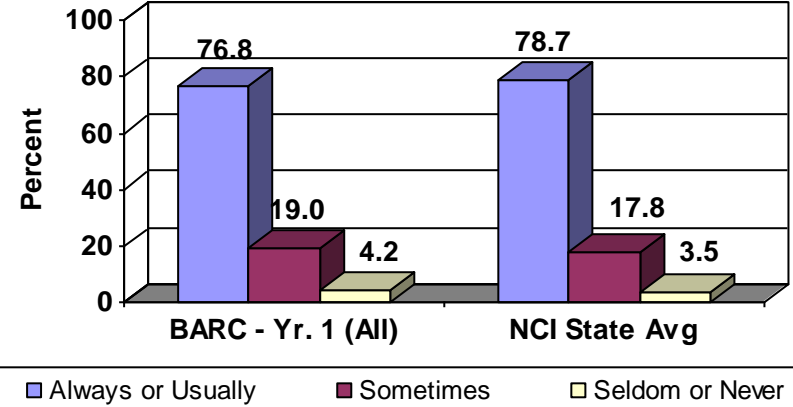
**Chart Q1**

Do you get enough information to help you participate in planning services for your family member?



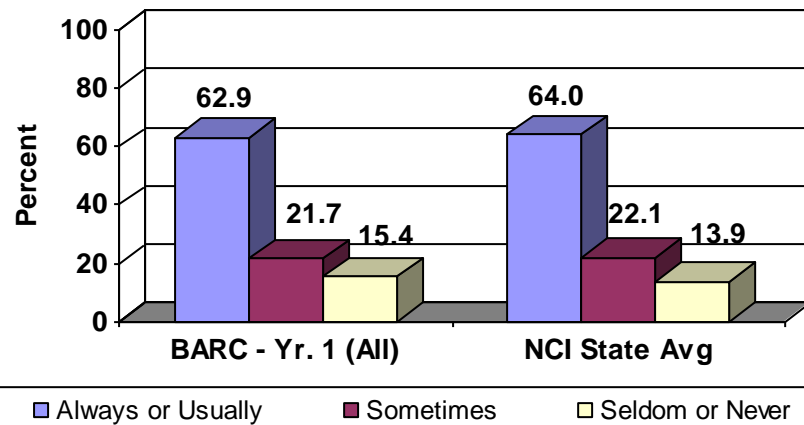
**Chart Q3**

If your family member has a service plan, does the plan include things that are important to you?



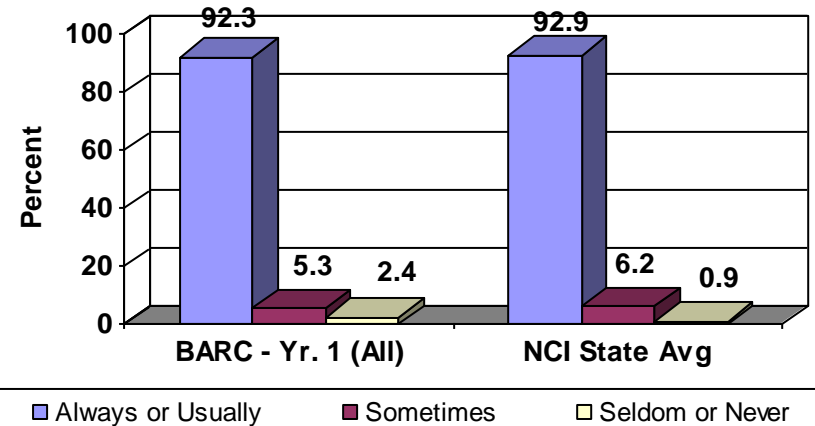
**Chart Q2**

If your family member has a service plan, did you help develop the plan?



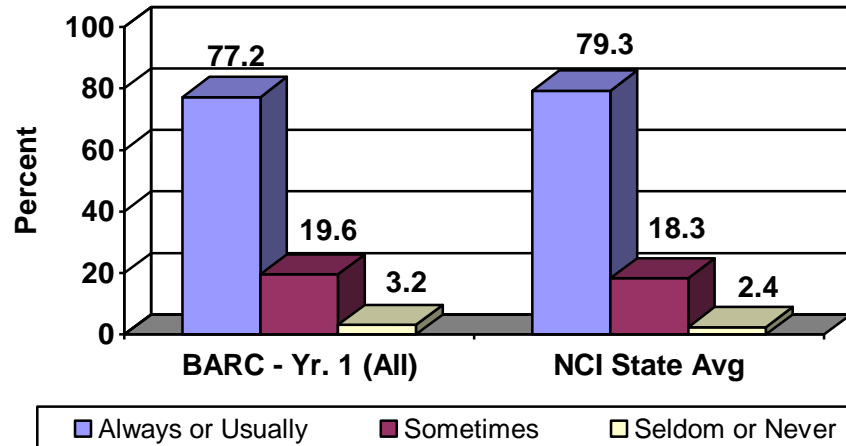
**Chart Q4**

Are the staff who assist you with planning generally respectful and courteous?



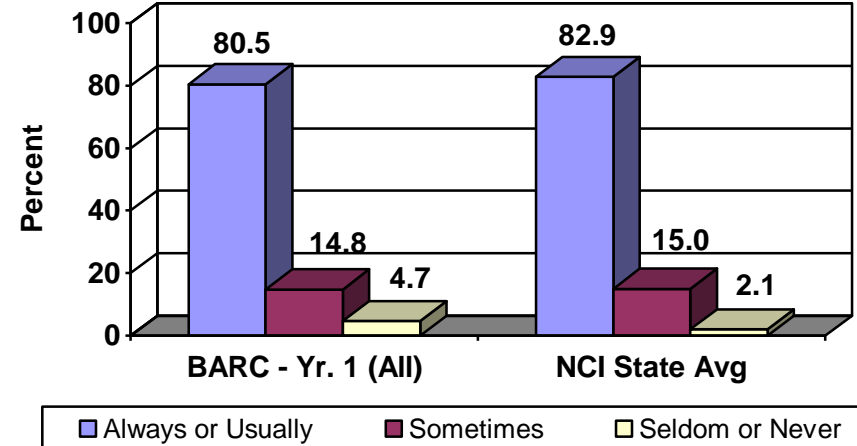
**Chart Q5**

Are the staff who assist you  
with planning generally effective?



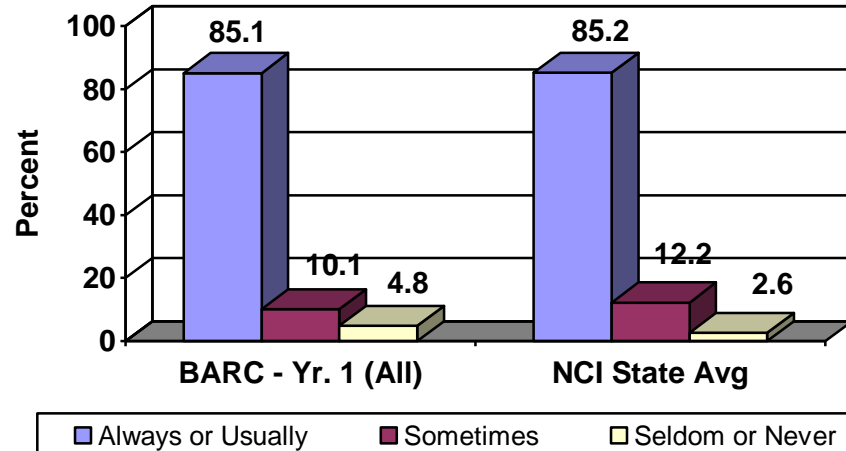
**Chart Q7**

When you ask the service coordinator/case manager for  
assistance, does he/she help you get what you need?



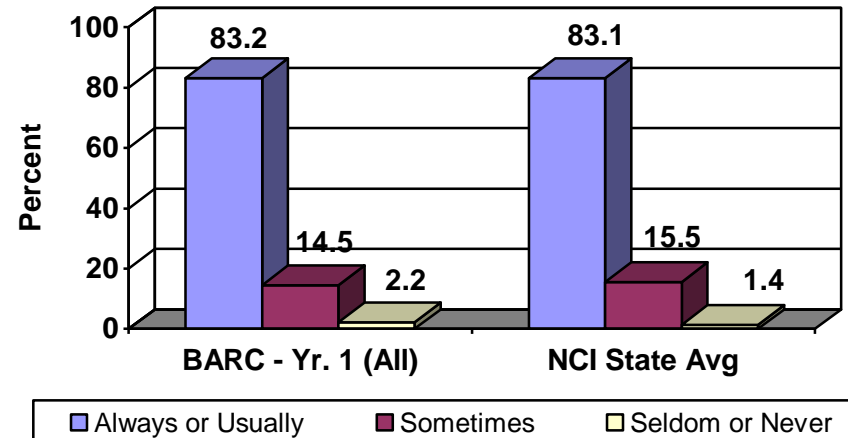
**Chart Q6**

Can you contact the staff who assist you  
with planning whenever you want to?



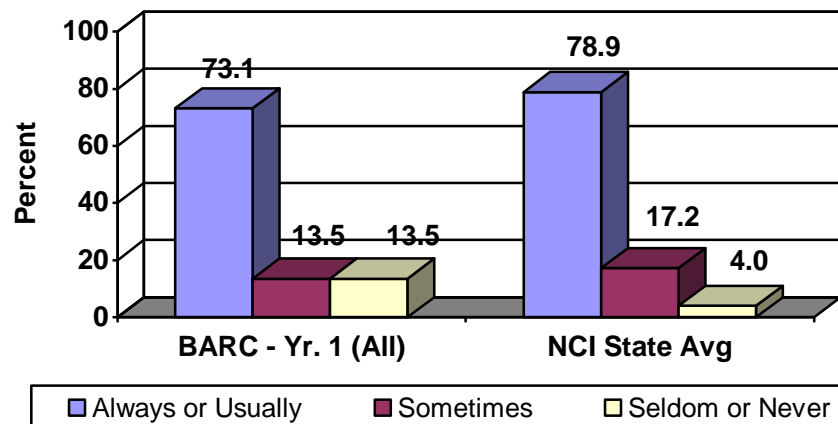
**Chart Q8**

Does your family member get the services  
and supports he/she needs?



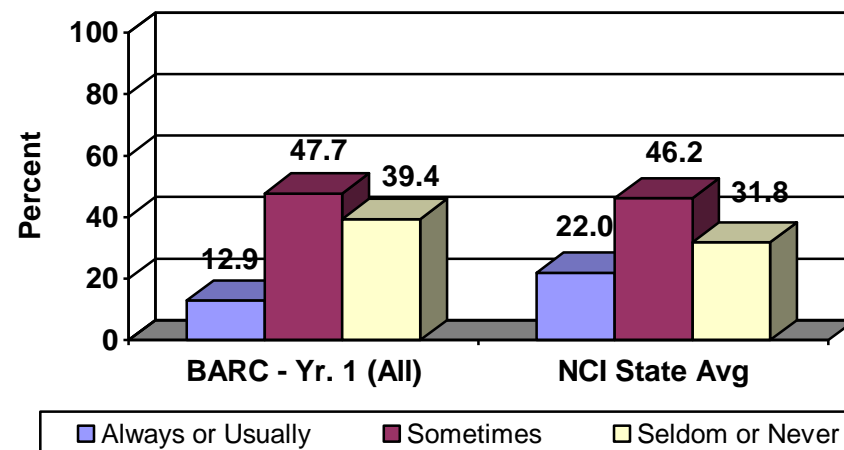
**Chart Q9**

If your family member does not speak English or uses a different way to communicate, are there enough support workers available who can communicate with him/her?



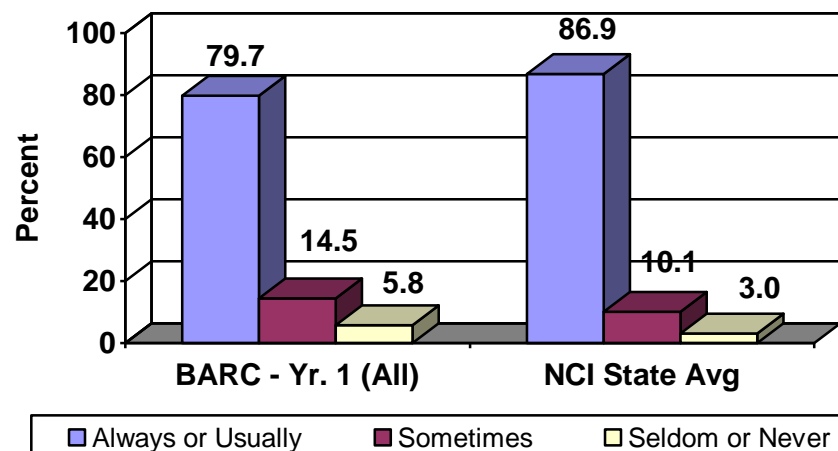
**Chart Q11**

Are frequent changes in support staff a problem for your family member?



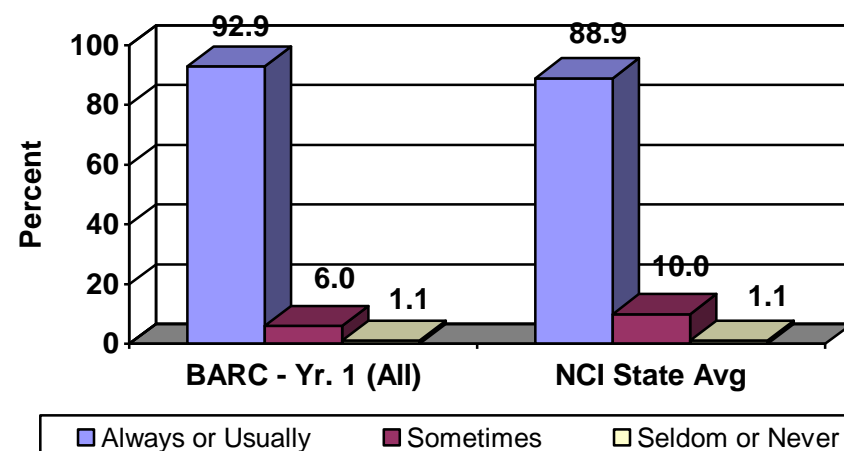
**Chart Q10**

Does your family member have access to the special equipment or accommodations that he/she needs?



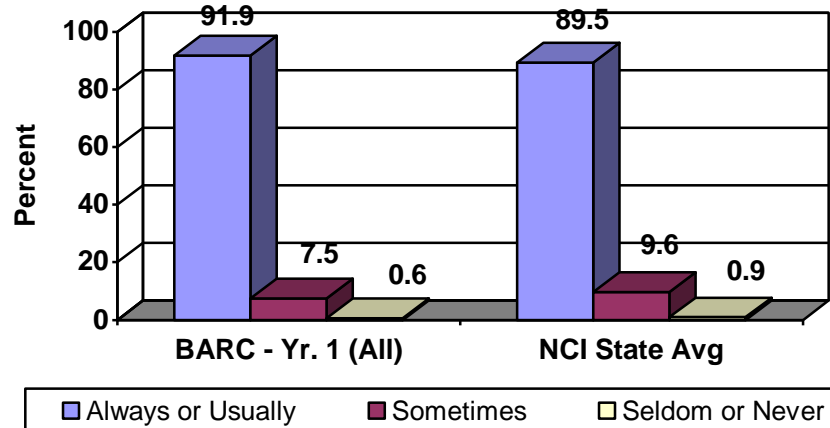
**Chart Q12**

Do you feel that your family member's residential setting is a healthy and safe environment?



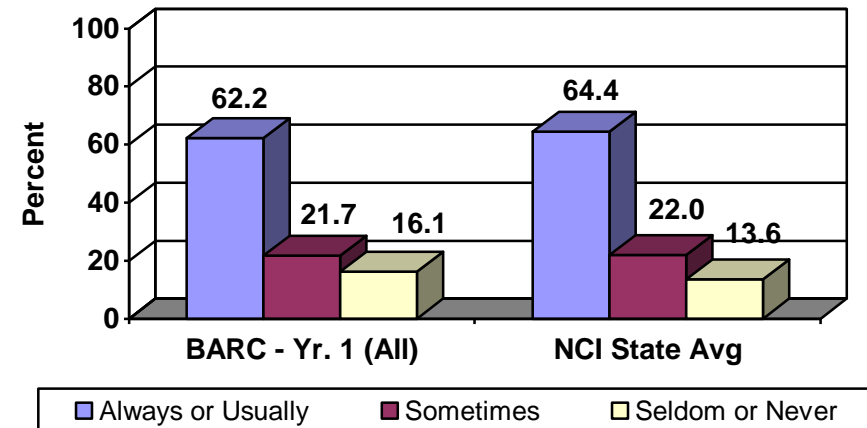
**Chart Q13**

Do you feel that your family member's day/employment setting is a healthy and safe environment?



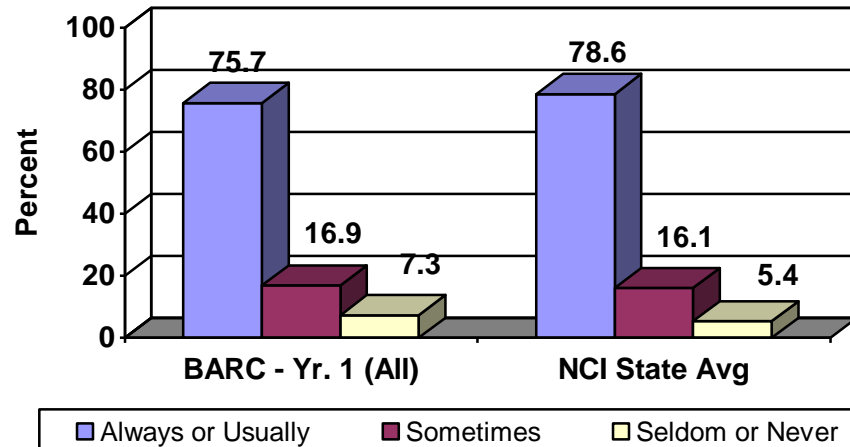
**Chart Q15**

If your family member gets day or employment services, does the agency providing these services involve you in important decisions?



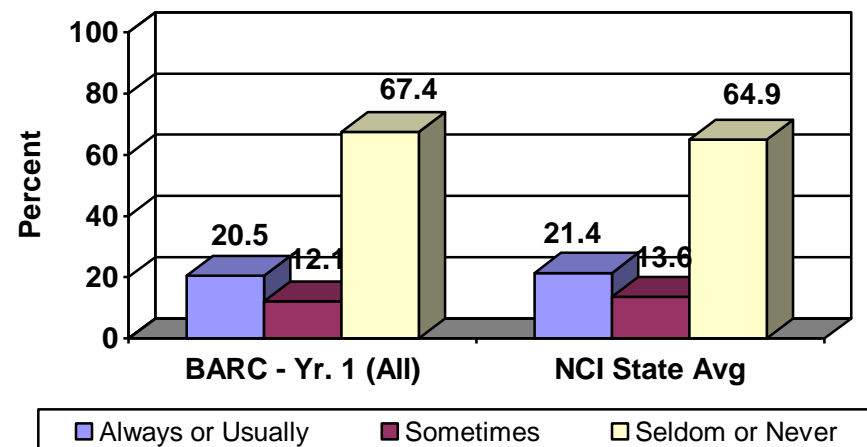
**Chart Q14**

Does the agency providing residential services to your family member involve you in important decisions?



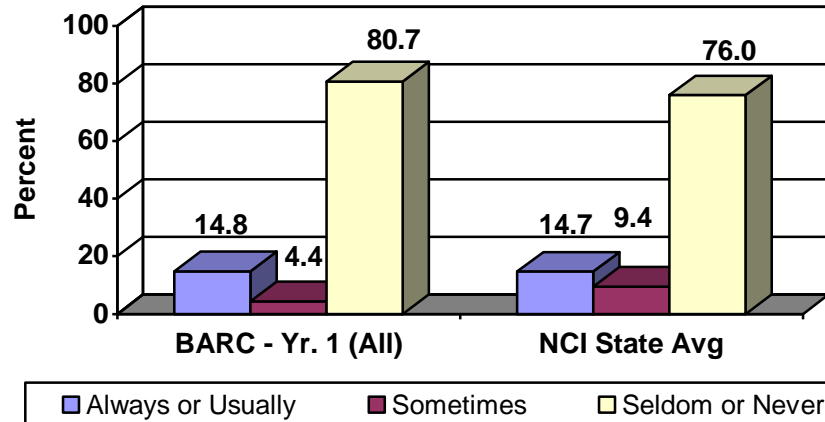
**Chart Q16**

Do you or your family member choose the support workers who work with your family member?



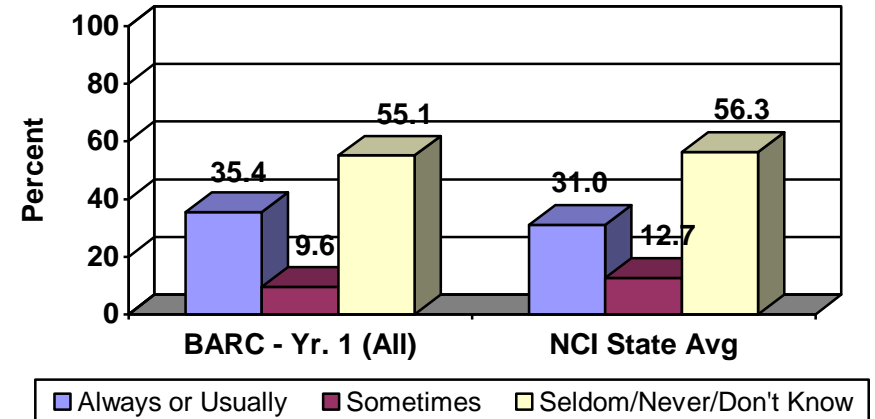
**Chart Q17**

Do you or your family member have control and/or input over the hiring and management of your support workers?



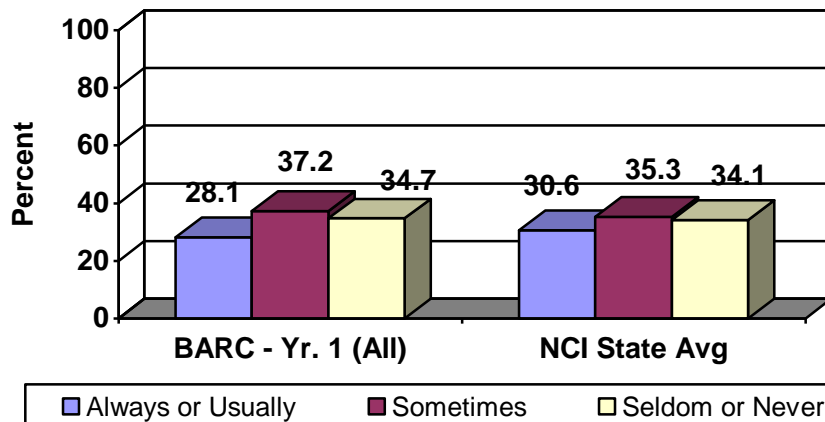
**Chart Q19**

Do you or your family member know how much money is spent by the MR/DD agency on behalf of your family member with a developmental disability?



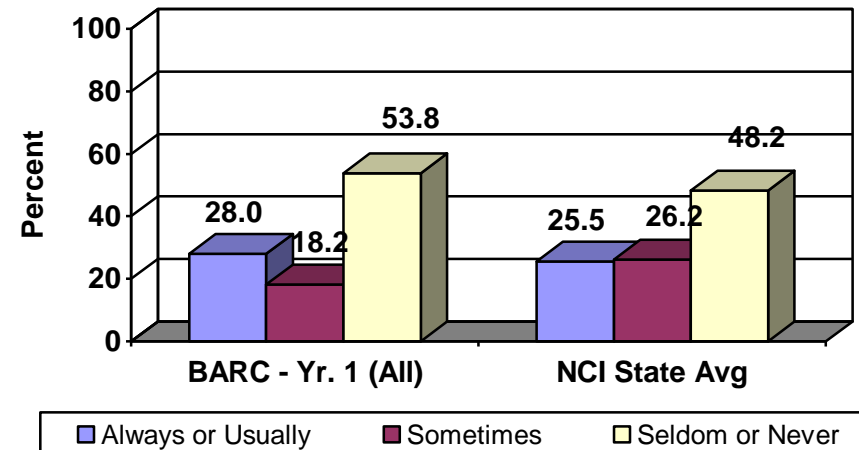
**Chart Q18**

Do you or your family member want to have control and/or input over the hiring and management of your support workers?



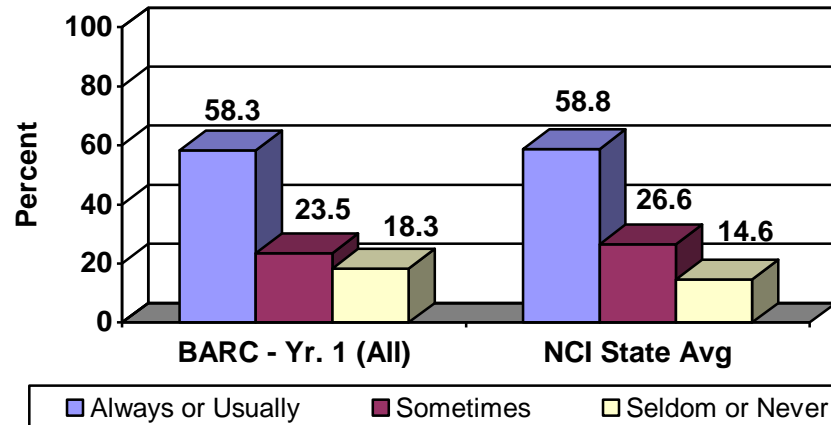
**Chart Q20**

Do you or your family member get to decide how this money is spent?



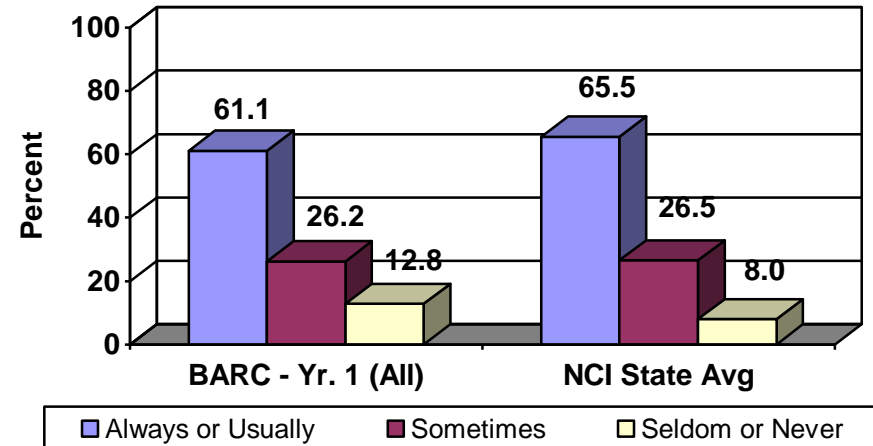
**Chart Q21**

If your family member wants to use typical supports in your community, do either the staff who help you plan or who provide support help connect you to these supports?



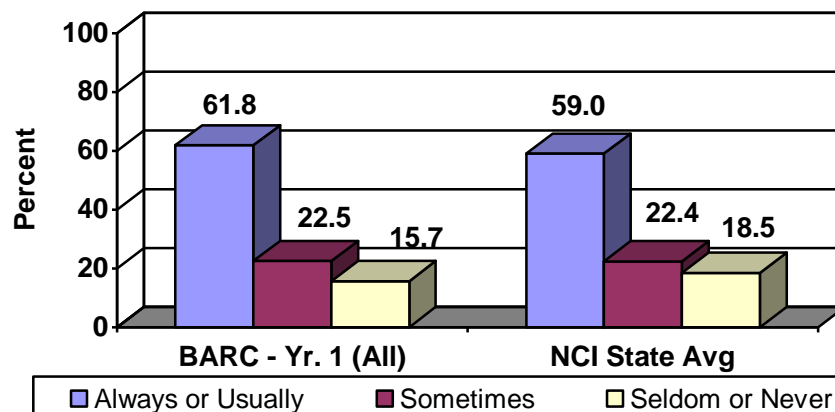
**Chart Q23**

Do you feel that your family member has access to community activities?



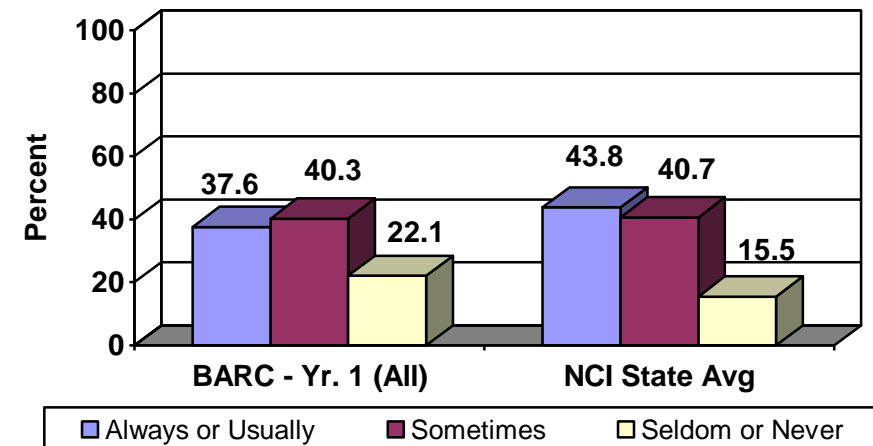
**Chart Q22**

If your family member would like to use family, friends, or neighbors to provide some of the supports he needs, do either the staff who help you plan or who provide supports help him do this?



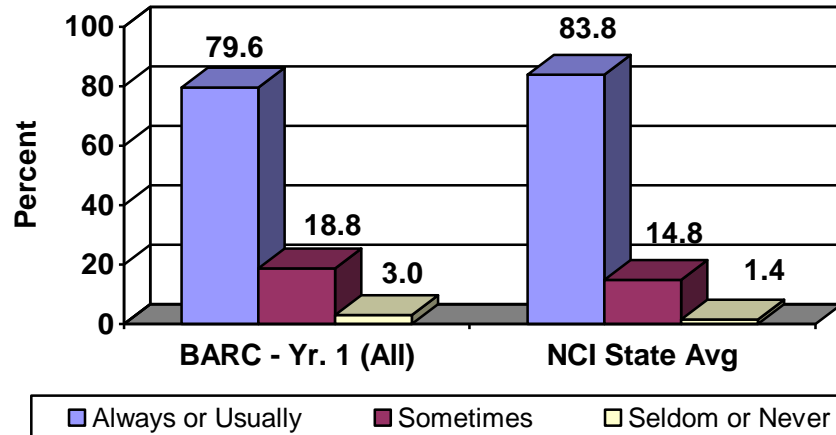
**Chart Q24**

Does your family member participate in community activities?



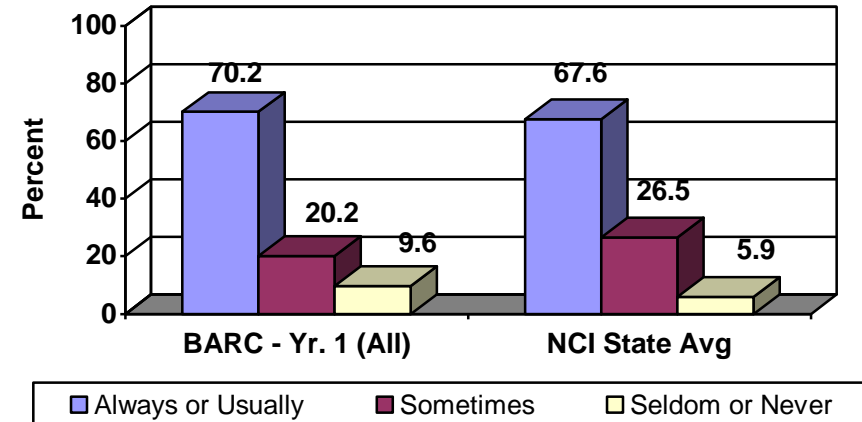
**Chart Q25**

Overall, are you satisfied with the services and supports your family member currently receives?



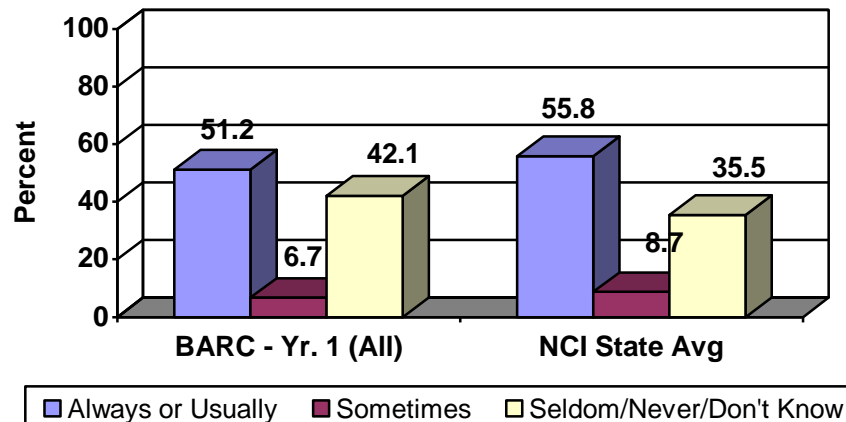
**Chart Q27**

Are you satisfied with the way complaints/grievances are handled and resolved?



**Chart Q26**

Are you familiar with the process for filing a complaint or grievance regarding services you receive or staff who provide them?



**Chart Q28**

Do you feel that services and supports have made a positive difference in the life of your family?

